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LAS DOÑAS: HEALTH LITERACY AND CERVICAL CANCER SCREENING AMONG OLDER MEXICAN-AMERICAN WOMEN

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LAS DOÑAS: HEALTH LITERACY AND CERVICAL CANCER SCREENING AMONG OLDER MEXICAN-AMERICAN WOMEN

by

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Dedication

To Hector, for always standing by me.

To Richie, for being with me from the beginning.

To Vicky, for all the time you waited and your undying belief in me.

To Jonathan, for keeping a smile on my face.

To my mother, for giving me hope for a better future.

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Abstract

Las Doñas: Health Literacy and Cervical Cancer Screening among Older Mexican-American Women

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Cancer is the leading cause of death for Hispanics, and cervical cancer incidence is higher (64%) for Hispanics than for non-Hispanic whites. In Texas Hispanic women 50 and older are the lowest screened and present with higher incidence of invasive cervical cancer as compared to non-Hispanic white women. They are diagnosed at a peak age of 65-74, which suggests that Hispanic women need to be screened past the recommended screening age.

An estimated 90 million people in the U.S. lack basic literacy skills and low literacy may contribute to low screening. Few studies have addressed the relationship between low health literacy and cervical cancer screening among older women of Mexican-American ancestry. This study sought to uncover the cervical cancer screening beliefs, practices, health literacy, knowledge, and experiences of English and/or Spanish-speaking older women of Mexican-American ancestry.

Thirty women participated in focus group or individual interviews in English and/or Spanish. Women 50 years of age or older living in the community were recruited

from senior centers in South Texas from a purposeful convenience sample. Data collection was conducted through audio-taped semi-structured interviews following a moderator guide developed using Zarcadoolas, Pleasant, and Greer's (2005) health literacy model. Data were transcribed, analyzed in original language, translated for meaning, aggregated for analysis using qualitative content analysis; matrices were developed and analyzed individually, and then data were aggregated. The Newest Vital Sign, a health literacy tool, was used to partially assess fundamental literacy.

Major themes elucidated were (a) Reasons "I don't go" [fundamental literacy], (b), Prevention of cancer and "everything else" [science literacy], (c) We are different,[cultural literacy], (d) There is always "consejos" (advice, messages) [civic literacy], and media literacy, (e) Telenovelas (soap-operas) teach a lot, and (f) Learning from Internet brochures.

The study supports a multidimensional model of health literacy and focus group research, accounting for the group's cultural norms, language, and educational preferences. It adds information for nurse clinicians about providing holistic care, for nurse educators regarding communication strategies for diverse older populations, and for researchers to continue developing strategies that improve health literacy and health outcomes for minority older women.

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Chapter One

Cancer Prevention and Health Literacy

Background and Significance

Cervical cancer is a preventable and treatable disease (Peragallo, Alba, & Tow, 1997; Saslow et al., 2002), yet more than 11,000 new cases are estimated to be diagnosed each year in the United States (Jemal et al., 2008) and 493,100 cases worldwide. It is the second leading cause of cancer in women (Kamangar, Dores, & Anderson, 2006), and its prevalence is highest among Hispanics. Mortality rates are 50% higher for Hispanic women than for non-Hispanic whites (American Cancer Society [ACS], 2006). In Texas, three in five cervical cancer deaths occur in women 50 and older; cervical cancer is the fifth most common site among Hispanic women in Texas compared to the tenth diagnosed site for all ethnic groups (ACS, 2008). Cervical cancer incidence rate for Hispanic women in Texas is 13.9 per 100,000 compared to 9.7 per 100,000 for non-Hispanic white women (Texas Cancer Registry, 2010).

Since cervical cancer is a preventable condition, health promotion practices including health screening are the keys to prevention. In fact, the U.S. Preventive Services Task Force (USPSTF) reported that consistent screening for cervical cancer would reduce the incidence of cervical cancer by up to 90% (2003). However, few older Hispanic women seek cervical cancer screening. Ramirez et al. (2000) reported that older Mexican American women residing in San Antonio, Brownsville, and Laredo, Texas, are less likely (fewer than 60%) to attend cervical cancer screening as compared to Central American women residing in San Francisco.

Cervical Cancer Screening

In the U.S., recommendations for yearly pelvic exams have been based on convenience (O'Connor, 2007; Waxman, 2005). Evidence now suggests that certain high-grade types of Human Papilloma Virus (HPV) cause most cervical cancers (O'Connor, 2007; Waxman, 2005). In general though, screening tests have contributed to the reduction of cervical cancer due to several factors:

> First, cervical cancer is a slow-growing process that spreads mostly by local extension; second, cervical cancer has precursor lesions that for the most part, also evolve slowly into malignancy; and third, the cervix is an accessible organ that can be sampled with minimal discomfort. (O'Connor, 2007, p. 182)

Given our understanding of HPV as well as the characteristics of cervical cancer, Papanicolaou (Pap) smear recommendations have changed to two to three year intervals at this time. Several organizations in the U.S. provide guidelines including The U.S. Preventive Service Task Force, which published its most recent guidelines in 2012; The American College of Obstetricians and Gynecologists ([ACOG], 2003); and The American Cancer Society (2002). There is agreement among the agencies to start Pap smears at age 21. Recently the USPTF (2012) reported that healthy women without risks factors after age 30 may extend the Pap smear interval to up to 5 years with a combination of HPV testing and Pap smear. There is a lack of a consensus among the groups regarding the age to discontinue Pap smear screening. ACOG (2009) recommended discontinuing Pap smears at ages between 65 and 70, provided that women have had three negative Pap smears in the past 10 years, negative risk factors, and negative history of abnormal cytology. ACS (2012) recommended age 65 with three

consecutive negative tests without abnormal tests within the last 10 years and negative risk factors. Similarly, the USPSTF (2012) recommended discontinuation at age 65 for those with a three consecutive negative cytology and no risk for cervical cancer. However, continued screening after age 70 was recommended for minority women, those whose prior screening is not documented, history of cervical cancer and other high risks such as immunocompromised women (Smith et al., 2011). The Association of Women's Health, Obstetric and Neonatal Nurses ([AWHONN], 2006) endorsed the HPV vaccine with continued routine screening, but it did not specify what is considered to be routine screening. These new guidelines require additional physician surveillance and educated patients (Waxman, 2005). Regardless of the frequency of Pap smears, annual exams are still recommended to assess for breast cancer and other gynecological problems (ACOG, 2012).

It is crucial to screen for cervical cancer and to correctly interpret the results based on a woman's risk factors (Warren, Gullett, & King, 2009). Risk factors associated with increased risk for cervical cancer include multiple sexual partners, early age at first intercourse, infection with HPV, tobacco use, male sexual behavior, and inadequate screening (Public Health Agency of Canada [PHAC], 2003; Reynolds, 2004). Older women ages 40-59 are at highest risk for cervical cancer (1 in 359) (Jemal et al., 2009), and often diagnosed in women not previously screened (Bernstein, DeJoseph, & Buchanan, 2010). Hispanic women have the lowest rate of cervical cancer screening and are diagnosed with invasive cervical cancer (ICC) at a peak age of 65-74. They have a higher incidence of ICC compared to non-Hispanic/Whites (Barnholtz-Sloan et al.,

2009). This finding suggests that minority women should continue to be screened past the current recommendations (Barnholtz-Sloan et al., 2009); therefore, it is crucial to understand factors related to low screening behaviors and high risk patients in order to provide adequate interventions that are culturally and linguistically appropriate. It is believed that one of the factors leading to inadequate screening rates is low health literacy (Lindau et al., 2002).

Literacy and Health Literacy

It is estimated that 90 million people in the U.S. lack basic literacy skills (Nielsen-Bohlman, Panzer, & Kindig, 2004). "Literacy can affect factors that determine our health such as our ability to secure employment, to have adequate income, and to engage in health enhancing behaviors" (Friedman & Hoffman-Goetz, 2008, p. 286). The 2003 National Assessment of Adult Literacy [NAAL] measured three types of literacy defined by Kutner et al. (2007) as follows:

> Prose Literacy: The knowledge and skills needed to search, comprehend, and use information from continuous tests. Prose examples include editorials, news stories, brochures and instructional materials.
>
> Document Literacy: The Knowledge and skills needed to search, comprehend, and use information from noncontiguous text. Document examples include job applications, payroll forms, transportation schedules, maps, tables, and drug and food labels.
>
> Quantitative Literacy: The knowledge and skills needed to identify and perform computations using numbers that are embedded in printed material. Examples include balancing a checkbook, figuring out a tip, completing an order form, and determining the amount of interest on a loan form from an advertisement. (p. iii)

Kutner et al. (2007) reported the 2003 findings of NAAL: 29% of individuals older than 65 had the lowest literacy score of *Below Basic* on all the above tests as

compared with 13% *Below Basic* in the 50-64 age group. Hispanics scored *Below Basic* (44%) as compared to Whites (7%). The majority of Hispanics surveyed were of Mexican origin, and about 3% of those surveyed were non-literate in English (Kutner et al.). It is reasonable to think that literacy skills are prerequisites to health literacy; therefore, individuals with low literacy would also have low health literacy skills (Nielsen-Bohlman et al., 2004). The 2003 NAAL report also included an assessment of health literacy (Kutner et al.).

Among Hispanic women, the rate of cervical cancer screening is at its lowest among elders. In a recent literature review, Flores (2009) found that, out of 56 studies, only seven were specifically conducted with women older than 40. Of those seven studies, only three were conducted with women over 50 years old. Only one study was found to address low health literacy in adults 65 and older. Scott, Gazmararian, Williams, and Baker (2002) concluded that Medicare enrollees with inadequate functional health literacy were less likely to report use of preventive health services, among them routine Pap smears. Little information is available regarding older, low health-literate women of Mexican origin and their efforts to obtain information about cervical cancer screening. Understanding the information needs of older Mexican American women about cervical cancer screening may provide the basis for future development of culturally and linguistically appropriate interventions.

Race, Ethnicity, and Culture

Race.

The U. S. Census (2010) recognized at least five racial categories: White; Black, African-American or Negro; American-Indian or Alaskan Native; Asian; and Native Hawaiian or Pacific Islander. Racial categories do not identify people by biological, anthropological, or genetic composition, rather the categories are a social definition of race as it is viewed in the U.S. Hispanic, Latino, or Spanish may be of any race. Race is an important and self-defining concept as well as a complex concept that poses certain complications due to migration, intermarriages, self-identification, and social category (Bulatao & Anderson, 2004).

Hispanic ethnicity.

The term *Hispanic* is used to designate people whose ancestry or origins are from a Spanish-speaking country. It derives from the use of a language (Cafferty & Engstrom, 2006), and the origin can be traced to Mexico, Puerto Rico, Cuba, and Spanish-speaking countries of South America or other Spanish cultures (U. S. Census Bureau, 2010). The U.S. Office of Management and Budget created the definition of Hispanic in 1978 that focuses on countries of origin, but it was not until 1996 that all states adapted the term to report mortality data. Data prior to 1996 for Hispanics do not exist since the only terms available were *white* and *other* (National Alliance for Hispanic Health, 2001). Ethnicity distinguishes groups by social characteristics including; language, history and customs; although there is an infinite number of racial and ethnic characteristics in the U.S., the 2000 census added Hispanic/Latino as an *ethnic* distinction (Bulatao & Anderson, 2004,

p. 9). Ethnicity is a social construct and relates to one's self -identity and lifestyle choice as a group member (Kagawa-Singer, Dadia, Yu, & Surbone, 2010).

In 2010, there were 50.5 million Hispanics in the U.S., or 14.8% of the total population, with a growth rate of 24.3% as compared to 6.1% of the total population (U.S. Census Bureau, 2010). Texas ranks second, next to California, with a population of more than 8 million Hispanics or 36% of the total population (Pew Hispanic Center, 2009; U. S. Census Bureau, 2010). Hispanics in the U.S. come from three major groups: Mexican (64%), Puerto Rican (9%), and Cuban (3.4%) (U.S. Census Bureau, 2006). In Texas, 88% of the Hispanic population is of Mexican origin (Pew Hispanic Center, 2008). Each Hispanic subgroup has distinct cultural orientations (Bagley, Angel, Dilworth-Anderson, Liu, & Schinke, 1995), distinguished by critical events or social events such as wars, new technologies and economic changes; these are some of the reasons Hispanic subgroups differ from each other (National Alliance for Hispanic Health, 2001). For example, Mexican Americans living in the United States since the acquisition of the Southwest states in the 1840s are very different from the Mexican families who have newly immigrated to the United States (Kagawa-Singer et al., 2010). Thus, racial and ethnic distinctions undermine the understanding of culture in which socioeconomic factors exert a greater influence over others, including race, culture, and ethnicity (Kagawa-Singer et al., 2010); but, more important, "it is the interaction of all these factors that determines health disparities" (Kagawa-Singer et al., 2010, p. 15).

Culture.

There are abundant definitions of culture without a clear definition in the health literature (Kagawa-Singer et al., 2010). Culture is a complex construct, but scholars agree upon several aspects: (a) culture is multilevel in adaptive interactions or it is a system of organizing information through symbols and behavior; (b) culture is shared; language represents one shared element of culture; (c) culture is formed over time, transmitted across generations, stable, and is essential to the survival of its members (see Andrulis & Brach, 2007; Kagawa-Singer et al., 2010; Taras, Rowney, & Steel, 2009). Transmission of cultural information may occur through mass media (Taras et al., 2009; Triandis, 1994). Culture helps its members find the meaning and purpose of life (Kagawa-Singer et al., 2010).

Taras et al. (2009) described culture as an onion with basic assumptions and values at the core of culture and where the outer layers represent practices, symbols, and artifacts. Culture can influence how people interpret health and health care attitudes and beliefs; it is related to health status (Triandis, 1994). Culture shapes human behavior since it is the human-made part of the environment along with biology and ecology (Triandis, 1994).

Culture requires its members to engage in collaborative activities; it is the collective group's agreement of social expectations and punishments for deviations from those norms (Tomasello, 2008). Cultural groups share collective ideas, meanings, and values (Nielsen-Bohlman et al., 2004) that impact health outcomes (Padilla & Villalobos, 2007). Culture is a structure that defines language, the meaning of words and symbols

(Nielsen-Bohlman et al., 2004). Triandis (1994) summarized culture as human-made with both subjective and objective factors which increased survival within its members with the ability to communicate with each other through language.

Language.

Without language, an integral component of culture, society, ethnicity, and social identity, individuals could not create a society (Gumperz, 1982; Kess, 1976). Language includes vocabulary rules and grammar. But language is more than its rules. According to Kess (1976), language is the structure through which thought and culture are linked, so what we think is dependent upon our culture. Language is connected to the real world through symbols as well as the social world of speakers. In other words, our first language spoken provides meaning and cultural context; a second language learned may not include the cultural context, (National Alliance for Hispanic Health, 2001); therefore, the meaning of words may be lost. In the U.S., Nielsen-Bohlman et al. (2004) found that a person's health literacy issues and health outcomes are worse when their English is limited. Spanish is the second language most used in the United States, and it is spoken by half of the non-English speakers in this country (National Alliance for Hispanic Care, 2001). The Spanish language has been used in the Southwest area of the United States for four centuries (Pfaff, 1979) and remains an important component of the Hispanic population living in Texas. Although many Hispanics learn English, often they retain their Spanish language (Cafferty & Engstrom, 2006). As reported by the Pew Hispanic Center (2008), 78% of Hispanics speak a language other than English at home. The Spanish language continues to be a present and strong component of the Hispanic culture.

Hispanic Culture

Certain cultural, core values or characteristics have been identified in the literature related to Hispanic culture and include:

Familismo (the family).

The value that family is central and a core value of Hispanic culture (Sabogal, Marin, Otero-Sabogal, Marin & Perez-Sable, 1987) where the nuclear family is the essential unit (Kemp, 2005). Although Hispanic extended family members are important and include not only parents and grandparents but also uncles and aunts, close friends may also be called aunts and uncles. Hispanic family honor and unity becomes a part of one's identity. Advice from other members is not only sought but also expected, especially when family members are ill. Family takes priority over the individual or the idea of interdependence rather than independence and cooperation rather than competition (National Alliance for Hispanic Health, 2001). Siblings are encouraged to maintain strong ties and parent-child bonds are important (Falicov, 2005). In medical consultations, older and younger members of the family may be included. A spokesperson for the patient may be a matriarch/patriarch of the family or someone who speaks English in the U.S. (National Alliance for Hispanic Health, 2001). Research conducted with Mexican Americans reveal the importance of *familism* on expectations and responsibilities for elder care. Elders anticipate being cared for by family members as they become frail. This is rooted in the belief, in particular of older Latina women, that frailty is a natural life course rather than an illness. In contrast, non-Hispanic whites

believe that becoming ill or frail will impose a burden on younger family members (Padilla & Villalobos, 2007).

***Respeto* (respect).**

Every person needs to be treated with respect, usually individualized by age or sex. For example; older individuals receive respect from younger ones or health professionals to patients, respect is mutual (National Alliance for Hispanic Health, 2001). Respect for parents from children is expected as well (Kemp, 2005). A sign of respect given by Hispanics to medical persons or those in authority is shown by avoiding eye contact, and certain topics maybe considered disrespectful, especially if asking direct questions related to alcoholism, mental illness or sexual practices. Giving respect to elders includes addressing them in a formal fashion such as using the terms *Señora* (Mrs.) or *Doña* (Madam); equally important is using the formal of *usted* (you), also a sign of respect (National Alliance for Hispanic Health, 2001).

***Personalismo* (personal, friendly).**

Establishing individual relationships rather than institutional relationships is important to Hispanic communities. A single word translation of *personalismo* into English is not available but includes such ideas as loyalty and honesty (National Alliance for Hispanic Health, 2001) as well as *confianza* (trust). Hispanics will be more likely to follow medical advice if there is *confianza* or trust that the provider has their best interest in mind; in other words, mutual trust among individuals exists (Castellanos, 2000). *Personalismo* also includes *simpatía* (friendly, polite). Hispanic expectations from the healthcare encounters may include all the above values.

***Marianismo* (women's characteristics).**

Positive female characteristics of Hispanic women include taking care of the household and taking on maternal roles. This view originates from the Catholic religion where the Virgin Mary represents the "ideal woman and mother" (Castellanos, 2000, p. 2), self-sacrificing and pure (Castellanos, 2000). Motherhood represents a higher status in Hispanic society where maternal love is greater than spousal love (Kemp, 2005). Publicly, women will respect the male role but privately many Hispanic women may impose a higher level of power within the family and in the decision-making process (Kemp, 2005). In addition, *marianismo* commands male respect, self-dignity, and family responsibility (Castellanos, 2000).

***Machismo* (male characteristics).**

Positive Hispanic male characteristics include hard worker, good husband, father, and son. The male is in charge of the family decisions. *Machisimo* gives Hispanic males a sense of self-identity and manhood (Kemp, 2005). They are responsible, keep their word, and protect their family honor (Cofresi, 2002). Negative characteristics of *machismo* include: aggressiveness, sexual promiscuity, excessive male pride and domineering (Castellanos, 2000; Cofresi, 2002; Kemp, 2005). *Machismo* is illustrated in Pena's (1991) field work in which he concluded that Mexican working men criticize Mexican American men for giving up their authority over women and giving them equality; soon all women "want to be like men" (p. 43) and "we all have to prove that we are men" (p. 43).

Cancer fatalism.

Cancer fatalism (death cannot be avoided) has been viewed as a barrier to cancer screening, many Latina women see it as a matter of fate, are more pessimistic about a cancer diagnosis (Bagley et al., 1995; Castellanos, 2000; Chavez, Hubbell, Mishra, & Valdez, 1997; Hubbell, Chavez, Mishra, & Valdez, 1996; Powe & Finnie, 2003; Wells, Cagle, & Bradley, 2006).

Mexican-Americans in the U.S.

Mexicans and Mexican Americans have been in the Southwest region of the U.S. for centuries, before the U.S. acquired what was then northern Mexico, now the Southwest of the U.S. Immigration policies of the U.S. have influenced the migration of Mexicans to the north; from encouraging labor, farm workers, and legalization to punishment, imprisonment, and retaliation (Falicov, 2005). Mexicans are both the first and last immigrants to the U.S. (Cafferty & Engstrom, 2006). The population of Mexican immigrants to the U.S. doubled from 1970 to 1980 and more than doubled from 1980 to 1990. Currently Mexican immigrants have the highest unemployment rates, are less educated, live in poverty and many are non-skill workers compared to other groups in the U.S. (Pew Hispanic Center, 2009). Parallel to the above description, many Mexicans are college educated and come to the U.S. for professional employment (Kemp, 2005). Many Mexican Americans live in urban settings and gather in neighborhoods that include similar foods, voices, and sites.

Mexican American women are descendents from the Ameri-Indians and Spanish Conquistadores of the 1500s that permanently settled in Texas in 1700. In the early

1900s, many Mexican women immigrated to Texas accompanying their husbands who often worked in the railroad. In the 1930s, many Mexican American women worked outside the home (Orozco, 2002). By the 1990s, many women had gained equal opportunity of education and employment in the U.S., but Mexican American women continued to experience lower wages, lower educational attainment, sexism, racism, and class barriers (Orozco, 2002).

Older Mexican-American women share the collective values of Hispanics. Eggenberger, Grassley, and Restrepo (2006) found that elderly Mexican American women's dominant value to be the family. Families relied on help from different generations; one participant noted, "I was there to help raise my three grandchildren… while my children worked" (Eggenberger et al., p. 8). The family as a social support as well as involvement in health care decisions was also evident in the interviews: "I took care of my Mom for nine years before she died" (p. 9). Older women are often the female role models for nurturing children: "I raised my children….that was my job" (Eggenberger et al., 2006, p. 9). In order to maintain a healthy family, women had pride in their family, maintained family cohesiveness, and displayed self-sacrifice; these were among the common themes that emerged in this study.

Researchers also found that religion plays an important role in older Mexican American women, in particular in times of illness or crisis. At the same time, women acknowledged their own actions as important in health outcomes and followed physician recommendations (Eggenberger et al., 2006). This study identified the dual roles of

external and internal locus of control; older Mexican American women were amenable to preventive health practices given proper recommendations and education.

Research may identify Hispanic/Latino as one group. For the purposes of this study, the terms will be used interchangeably. Few researchers make distinctions between Hispanic subgroups; this lack of distinction between Hispanic subgroups is one of the major gaps in the literature since *Hispanic* is a large umbrella term used to describe a heterogeneous group of people (Ramirez & de la Cruz, 2003).

Statement of the Problem

Cervical cancer screening is lowest among older Mexican American women in the U.S. Low health literacy may contribute to lower rates of screening among these populations. Few studies have documented the relationship between low health literacy and low rates of cervical cancer screening among older women of Mexican American ancestry. Therefore, the purpose of the study is to:

1. Explore the cervical cancer screening beliefs and practices of English and/or Spanish speaking older women of Mexican American ancestry.

2. Describe the health literacy knowledge and experiences of English and/or Spanish speaking older women of Mexican American ancestry as they relate to cervical cancer screening following Zarcadoolas, Pleasant, and Greer's (2005) multi-dimensional model of health literacy which describes four main domains; fundamental literacy, science literacy, cultural literacy and civic literacy.

Research Questions

1. What are the cervical cancer screening beliefs and practices of English and/or Spanish speaking older women of Mexican American ancestry?

2. What are the health literacy knowledge and experiences of English and/or Spanish speaking older women of Mexican American ancestry related to cervical cancer screening following Zarcadoolas et al., (2005) health literacy model.

Conceptual Framework

A health literacy conceptual framework that takes into consideration the complex interactions of culture, ethnicity, educational, political, and socio-economic differences of older women of Mexican American ancestry guided this study. In 2005, Zarcadoolas, Pleasant, and Greer proposed a conceptual framework of health literacy, one that "evolves over one's life" (p. 196). It is a complex, non-linear, multi-dimensional model and related to multiple human factors including health status, culture, demographic, social, political, and psychological factors. Defined as "the wide range of skills, and competencies that people develop to seek out, comprehend, evaluate and use health information and concepts to make informed choices, reduce health risks and increase quality of life" (Zarcadoolas et al., 2005, p. 196), this model provided the theoretical guidance for the study, which describes four domains: fundamental literacy, science literacy, civic literacy, and cultural literacy.

Low health literacy has been associated with poor cancer screening knowledge and practices. Low health knowledge and decreased use of preventive care services have been strongly associated with higher mortality rates when compared to women with

higher literacy levels who demonstrate increased knowledge regarding the purpose of a Pap smear (Baker et al., 2007; Kutner et al., 2007; Lindau et al., 2002). Furthermore women with low literacy skills were more likely to panic or do nothing (30%) for abnormal Pap results as compared to women with adequate literacy skills (19%) (Lindau et al., 2002). The four domains of the model are defined as follows from Zarcadoolas et al. (2005).

Fundamental literacy.

These are skills necessary to read, write, speak, and understand numbers (Zarcadoolas et al., 2005). According to the U.S. Census Bureau (2006), 23% of Hispanic female population has less than a ninth grade education compared to 6.7% of the total U.S. population. Although gains in educational attainment have improved, low literacy among Hispanics will continue to exist as they continue to have disproportionate dropout rates as compared to non-Hispanic whites. According to the Compendium Report of the National Center for Educational Statistics (Chapman, Laird, & KewalRamani, 2010), the latest statistics indicate that the Hispanic dropout rate has decreased from 35% in 1980 to 18% in 2008. Among Hispanics; Mexican Americans have the lowest high school graduation rate (48.7%) compared to Cuban Americans with (68.7%). The problem of limited fundamental and science literacy will continue to predominate due to lack of basic education and literacy. To compound the problem of low literacy, a wider gap exists between older (age 65 and over) Hispanics and non-Hispanic whites. High school attainment for this age group is 42% for older Hispanics compared to 82% for non-Hispanic whites (Federal Interagency Forum on Aging-Related Statistics, 2010). Along

with three other states, Texas ranks highest in the number of people 24 and younger without a high school education. Similarities among all four states include a large concentration of Hispanics, many of whom are foreign born, together with poverty (U.S. Census, 2000). Hispanics with higher rates of lower educational attainment may predispose individuals to low health literacy skills and decreased health outcomes.

Science literacy.

Literacy in the sciences is described as the level of competence with science, technology, and an awareness of the scientific process including (a) knowledge of fundamental science, (b) understanding and comprehension of technology, and (c) understanding of scientific uncertainty and change (Zarcadoolas et al., 2005).

The minimum knowledge needed or science literacy related to cervical cancer, its precursors, and prevention would continue to be limited in Hispanic populations. Studies found that Hispanic women who had less education, less knowledge, and were less acculturated had decreased use of Pap smear screening (Bretikopf, Pearsons, & Bretikopf, 2005; Maed, Calvo, & Cuthbertson, 2002; McMullin, De Alba, Chavez, & Hubbell, 2005; Scarinci, Beech, Kovach, & Bailey, 2003; Suarez, Roche, Nichols, & Simpson, 1997).

This lack of knowledge may be more prevalent in older individuals, who are less likely to have fundamental literacy skills as indicated by the NAAL (2003) survey (Kutner et al., 2007). In addition researchers found older Hispanic women were less knowledgeable about cervical cancer than younger cohorts and were the least likely to be

screened for cervical cancer (Coughlin, Uhler, Richards, & Wilson, 2003; Mandelblatt et al., 1999; Ramirez et al., 2000; Suarez, Roche et al., 1997).

Civic literacy.

As the ability to be aware of public issues and participate in decision-making, this category includes (a) media literacy, (b) knowledge of civic and government process, and (c) awareness that individual health decisions can impact public health (Zarcadoolas et al., 2005). Media literacy is the ability to analyze, learn and create "one's own message in print, audio, video or multimedia" (Hobbs, 1998, p. 16). The private sector has learned to tap into Hispanic language and culture by advertising in Spanish, although messages conveyed are directed to marketing of products and of Western culture (Cafferty & Engstrom, 2006). In the government arena, ballots as well as other literature have been translated into Spanish, giving Hispanics a wider opportunity to participate in the political process. Yet, those who want to fully participate in American society will need to speak English since it is considered the driving force of the American economy (Cafferty & Engstrom, 2006). Older Mexican American women whose cultural values may be stronger than those of younger women may experience additional barriers to civic literacy and be unaware of the importance of cervical cancer screening and its personal and societal impact.

Cultural literacy.

This ability to use beliefs, customs, and social identity to interpret and act on health communication also includes the communicator's ability to deliver health information that is culturally appropriate. Hispanic women's beliefs about cervical cancer

were associated with promiscuous sexual activity, such as many sexual partners at the same time (Guilfoyle, Franco, & Gorin, 2007; McMullin et al., 2005; Vanslyke et al., 2008). Hispanic women consider sexuality a very private matter (Hubbell et al., 1996) and may be reluctant to talk about it, especially if there is a lack of *confianza* (trust) between the patient and the provider (Guilfoyle et al., 2007; McMullin et al., 2005; Pinzon-Perez, Perez, Torres, & Krenz, 2005; Vanslyke et al., 2008). Fear of cancer, or, as it has been termed in the literature, fatalism (the idea that everything is left up to fate and there is little one can do to change the course of fate), or the idea of preferring not to know a cancer diagnosis, was a recurring theme among cultural Hispanic beliefs discussed in several articles (Arredondo, Pollak, & Costanzo, 2008; Behbakht, Lynch, Teal, Degeest, & Massas, 2004; Guilfoyle et al., 2007; Powe & Finnie, 2003).

Another predictor of Pap smear screening behaviors among Hispanic women is the level of acculturation defined as change "not only at the individual or psychological level but also at the sociocultural level" (Chun, Organista, & Marin, 2002, p. 5). Hispanic women who were found to be less acculturated as measured by language spoken at home were found to have decreased use in Pap smear screening (Shah, Zhu, Wu, & Potter, 2005). In contrast, Abriado-Lanza, Chao, and Gates (2005) found that acculturation did not predict recent Pap smear screening (odds ratio 1.38, 95% confidence, CI=0.99). Indeed, acculturation measurements require more than language spoken at home, language learned as a child, or self-identification.

Acculturation involves the "influence of social and environmental changes on an individual's values, beliefs, behaviors, and affect" (Chun et al., 2002, p. 5). Instruments

used to assess acculturation vary in content, but "it is unclear whether any of these measures have adequately sampled the various behavioral and attitudinal domains in which acculturative change would be expected to occur" (Chun et al., 2002; p. 52). Hispanic women's cultural beliefs are associated with decreased use of Pap smear screening that encompasses more than language alone.

Language, another major component of culture, is used to compare participants proficient in English to those proficient in Spanish. English proficiency has been described in the literature as positively correlated with higher rates of Pap smear screening as compared to Spanish-speaking only women (Arredondo et al., 2008; De Alba, Sweningston, Chandy, & Hubbell, 2004; Jacobs, Karavalos, Rathouz, Ferris, & Powell, 2005).

The majority of studies related to cervical cancer screening do not identify the Hispanic subgroup. Although Hispanics share the Spanish language as a commonality, they do not represent a homogenous group. Although the Spanish language has been used in the Southwest area of the United States for four centuries (Pfaff, 1979), there is significant within language variety associated with the Spanish language. In the U.S., common Spanish words in one region may have different meaning in another region of the country. Code switching, or changing languages English/Spanish, is a common practice driven by social motivators (Pfaff, 1979), where standard dictionary translations do not apply (Vasquez, Pease-Alvarez, & Shannon, 1994). Examples include "Como, here you can because viven todos juntos" "Like…they live all together" (Pfaff, 1979; p. 312). Standard Spanish language is mostly used by older adults; "for them, good

Spanish means the Spanish of Mexico" (Pfaff, 1979; p. 293), while popular Spanish (Tex-Mex, Pocho, or Mixteado) is more common in adolescents (Pfaff, 1979). These differences in meaning present difficulties for researchers when instruments or interviews are translated and back-translated from English to Spanish without taking into account the regional and colloquial differences (Kruger, 1998a). Similarly, women may prefer to express themselves in Spanish if words in English do not describe the meaning of a personal matter such as Pap smears.

The conceptual framework described by Zarcadoolas et al. (2005) was used to frame the present study; focus group questions followed the domains of science literacy, civic literacy, and cultural literacy. The domain of fundamental literacy was partially assessed by Weiss et al. (2005) *The Newest Vital Sign* (NVS), a short literacy assessment tool. This researcher believes that the intersection of health literacy, culture, and language to explore older Mexican American women's cervical cancer screening serves as a base for research and community education and as a first step to decrease cervical cancer mortality rates among this population.

Assumptions

Older women of Mexican American ancestry experience cultural, linguistic, communication, and educational barriers related to preventive health care, more specifically, cervical cancer screening.

1. Women will be open and honest with their opinions during interviews.

2. Older women of Mexican American ancestry will be able to openly give their opinions since researcher is bicultural, bilingual, and will adhere to cultural core values.

Delimitations

The study was conducted with community-dwelling Mexican American women from a metropolitan area in South Texas using a purposive sample. Study findings cannot be generalized to other Hispanic subgroups, rural women, nursing home residents, men, or Mexican American women residing in other states.

Limitations

Limitations inherent of focus group interviews include (a) all individuals are not able to discuss topics in the same manner and (b) researcher presence may bias the discussion.

Summary

Given the low cervical cancer screening rate of older women of Mexican American ancestry, the prevalence of low health literacy, and, in particular, those for whom Spanish is their primary language, it is surprising that very few studies have specifically addressed the health literacy experiences, information-seeking behaviors, and preferences of educational materials about this disease and this population (Gabers & Chiasson, 2004; Scott et al., 2002). Therefore, the goal of the present study was to address these matters as a first step toward the design and implementation of appropriate interventions to close this health disparity.

Chapter Two

Review of the Literature

Cervical cancer is a treatable condition if diagnosed early through screening (ACS, 2002; Reynolds, 2008). However, Texas has one of the highest cervical cancer death rates in the U.S. (Centers for Disease Control and Prevention ([CDC], 2006), see Appendix A), and especially for Hispanic women over the age of 50 (Appendix B). The mortality rate for cervical cancer in Hispanic women is 13.2 per 100,000 as compared to 8.2 per 100,000 for non-Hispanic white women and 8.4 per 100,000 for all races (National Cancer Institute, 2008). It is believed that a low rate of cervical cancer screening among ethnic minorities is the major contributor to this statistic. Indeed, studies indicate that only a small number of older Hispanic women seek cervical cancer screening (Fernández-Esquer et al., 2003; Ramirez et al., 2000). Therefore, one objective of Healthy People 2010 was to increase the proportion of Hispanic women who receive a Pap smear to 85% (U.S. Department of Health & Human Services, 2000).

Several barriers to cervical cancer screening have been identified. These variables include cultural beliefs, socioeconomic status, education level, and low literacy (Boyer, Williams, Callister, & Marshall, 2001). A projected increase in older Hispanic women with low literacy may lead to higher rates of cervical cancer deaths for Hispanic women, if health literacy interventions are not implemented (Lindau et al., 2002). For the purposes of this review, the terms *Hispanic/Latino* will be used interchangeably and, when possible, the subgroup Mexican American will be used.

This literature review will address cervical cancer screening, health literacy, and the gaps in the literature associated with older women of Mexican American ancestry, cervical cancer screening, and health literacy.

Cervical Cancer Screening

Dr. George Papanicolaou, a Greek immigrant working at Cornell University Medical College while studying vaginal cells came across a woman with undiagnosed cervical cancer. His initial test involved using a pipette to retrieve vaginal cells without a speculum and, the test, therefore, acquired the name we recognize as the Pap test (Howell, Wilton, Bishop, Afify, 2009; O'Connor, 2007; Waxman, 2005). The Pap test is accepted by the public and is a low cost, effective tool in cervical cancer prevention, especially if repeated over time (Waxman, 2005). Cervical cytology or Papanicolaou smear is considered one of the great successes against cervical cancer prevention, although it is not the case for underserved populations in the Unites States (Scarinci et al., 2010).

In 1980 HPV (Human Papillomavirus) was linked to premalignant and cervical cancer by zur Haunsen (O'Connor, 2007), and in 2007 the Food and Drug Administration approved the HPV vaccine (Howell et al., 2009). There are 15 types of high risk HPV, which cause almost all cervical cancers in the world, considered a common sexually transmitted disease. Many infections of HPV resolve on their own while others progress to precancerous lesions (Scarinci et al., 2010). As a result, a new model of cervical carcinogenesis has emerged (a) HPV acquisition, (b) HPV persistence vs. clearance,

(c) progression of a persisting infection to cervical cancer, and (d) invasion (Scarinci et al., 2010).

The Pap smear receives an A in the recommendations rating by the USPSTF on a scale from A to E where A is *good evidence to support* and E *good evidence against* (Gates, 2001). Although the benefits of cervical cancer screening are well established it is not without controversy. Controversies regarding cervical cancer screening include age to stop and new technologies (Gates, 2001). The benefits must be considered against the possible harm from the test and included when counseling women. Harms associated with cervical cancer screening may come from increased testing, additional procedures and undue anxiety. Similarly harm related to HPV testing may include stigma and partnership discord (Bernstein et al., 2010; USPSTF, 2003).

After decades of Pap smear testing and recommendations for screening from the American Cancer Society since1945 (Howell et al., 2009), the overall mortality rate in the United States from cervical cancer has decreased by 70% from 1955 to 1992 and continues to decline by 4% each year (ACS, 2010). Despite these improvements, Hispanic women in the United States have higher incidence of cervical cancer (ACS, 2010); women older than 44 years old having low income, low education, and being born outside of the United States reported low Pap smear tests. Among reasons given for not attending Pap test among those surveyed; half did not specify a reason (Hewitt, Devesa, & Breen, 2004).

Fear and uncertainty have been reported as reasons for not attending regular Pap smear screenings. In a systematic review, Akerson and Preston (2009) found fear of

screening to be both a barrier and a motivator to cancer screening. On the one hand, women decided not to attend screening due to fear of medical exams, procedures, and lack knowledge. On the other hand women's fear of cancer was also a motivator for screening, especially if women followed provider recommendations and had trust in the medical personnel. Therefore, authors conclude that the source of fear had a different effect on behavior.

In a systematic review, Johnson, Mues, Mayne, and Kiblawi (2008) followed the four domains of the Health Belief Model including perceived barriers, perceived susceptibility, cues to action and perceived benefits, and sociocultural factors that influence cervical cancer screening among minority immigrant populations, including Hispanic, Asian, Middle Eastern, and African. Perceived barriers to cervical cancer screening were associated with fatalism, fear of diagnosis, fear of pain, distrust of the health care system, embarrassment, lack of knowledge about cervical cancer, and poor hygiene among ethnic groups in the U.S. Barriers reported among Hispanics included fear of not receiving treatment related to immigration status, fear of informing a partner about a cancer diagnosis, and fear of surgery. Perceived susceptibility among Hispanic beliefs included timing of sexual intercourse, immorality, and stress on the body. Cues to action to cervical cancer screening differed among ethnic groups. Cues for Asian, Hispanic, African American, and Middle Eastern in the U.S. included physician recommendation, family support, as well as comfort and respect. Among Hispanic groups, cues to action to cervical cancer screening included *promotoras* or lay health care workers. Perceived benefits to cervical cancer screening among Asian, Hispanic and

African American populations included early detection and the expectation of a longer life. In relation to perceived severity Hispanic populations believed that "cervical cancer would make life difficult, it is easily cured, and it is not as serious as other forms of cancer" (Johnson et al., p. 237).

Research conducted in England found women with close friends or relatives with cancer were more likely to attend screening (Adab et al., 2003), while Akerson and Preston (2009) reported women without a family history of cervical cancer perceived less risk and were less likely to participate in regular Pap smear screening. These findings indicate some discrepancies in cervical cancer screening research.

A systematic review by Black, Yamada, and Mann (2002) reported interventional strategies shown to improve cervical cancer screening and greatest effectiveness were those studies that included mass media campaigns along with tailored education. This review showed that Pap smear improvement rates varied from 12% to 61% compared to control groups. The greatest improvement for Pap smear rates (61%) was obtained from the use of an education video (Black et al., 2002). A summary table represented the target populations; only one study out of 21 identified Mexican American women. Similarly in a quasi-experimental design study in two clinics of mostly Latino and African-American low-income women, Yancey, Tanjasiri, Klein, and Tunder (1995) reported statistically significant improvement ($p < 0.05$) in Pap smear utilization by using culturally sensitive videos. Population characteristics represented on a table under the term *race* that included Latina representation varied from 55.7% to 75.4%. In addition, mixed results have been reported on the use of reminder letters to improve cervical cancer screening. Buehler and

Parsons (1997) reported no statistically significant difference noted in the study between women receiving a letter vs. those women not receiving a letter, while a study conducted in Italy by Segnan, Senore, Giordano, Ponti, and Ronco (1997) found women were more likely to attend cervical cancer screening if the letter included a time and date of appointment. Personalized letters with generic cancer information may also improve the rates of cervical cancer screening among minority women ($p< 0.001$). The population characteristics were described on a table under the heading *ethnicity*; African-American representation ranged from 38.0% to 43.5%, Mexican American, 39.7% to 44.8%, and non-Hispanic white, 16.8 % to 18.8% (Jibaja-Weiss, Volk, Kingery, Smith, & Holcomb; 2002). In addition, a study conducted in Australia found that the use of computerized based programs may increase Pap smear screening among older women ages 50-70, although the results were not statistically significant. The authors concluded that a small sample size might have contributed to the non-statistical significance (Campbell, Peterkin, Abbott, & Rogers, 1997).

Studies have reported increased Pap smear screening in clinics using Nurse Practitioners. Mandelblatt et al. (1993) reported a 92% increase in same day Pap smear screening among elderly women. Participants' mean age at baseline was 78 years old at the intervention site and 76.8 for post intervention. Hispanic representation at baseline was reported from 0.5% to 1.9% and 1.3% to 6.0% for post intervention. Margolis, Lurie, McGovern, Tyrrell, and Slater (1998) reported a 64% increase in cervical cancer screening in clinics that used lay health care workers and had a Nurse Practitioner available to perform screening. Participants' mean age ranged from 54.8 for those

receiving usual care for cervical cancer screening and 53.7 for the intervention group. Participants' race was reported as White, African American, Native American, and other; there was no mention of Hispanic ethnicity in this study. Although the use of lay health care workers has resulted in mixed results, Sung et al. (1997) did not find an effect on Pap smear screening among inner-city African Americans and concluded that additional strategies are needed to improve cervical cancer screening. Although studies have reported increased Pap smear screening using different interventions strategies, Ellis et al. (2005) in a systematic review of five cancer control interventions including mammography, smoking cessation, healthy diet, and cervical cancer screening concluded that there was lack of evidence to recommend any one-cancer control dissemination approach. However, the authors recommended an emphasis on community-based interventions that take into account the culture and beliefs of the group. The use of this approach has shown promise in changing behavior and prevention of cervical cancer (Scarinci et al., 2010). Studies addressing cervical cancer screening in Hispanic populations are limited. From the studies included in this review one had up to75.4% Hispanic population (Yancey et al., 1995), while others had no Hispanic representation at all (Margolis et al., 1998). In addition there is inconsistent use of the terms race and ethnicity making comparisons difficult.

Cervical Cancer Screening and Hispanic Women

The literature review related to Hispanic/Latino women and cervical cancer screening indicated several broad categories, including (a) limited knowledge, (b) cultural beliefs, (c) age, and (d) health insurance.

Limited knowledge.

Few studies examine the relationship between health literacy and health outcomes and limited knowledge is often omitted from the health literacy research (AHRQ, 2004). Nevertheless studies reporting limited knowledge of etiology, understanding and prevention of cervical cancer were negatively correlated with Pap smear use among Latina/Hispanic women (Arredondo et al., 2008; Bretikopf et al., 2005; Harmon, Castro, & Coe, 1996; McMullin et al., 2005; Scarinci et al., 2003; Vanslyke et al., 2008). McMullin et al. (2005) reported quotes from participants related to lack of knowledge and cervical cancer. One participant responded, "I have heard that when a person gets cysts there, they say that there, from cysts, cancer develops" (p. 5).

Furthermore, several studies have found that older Hispanic women had significantly lower levels of related knowledge and were the least to follow cervical cancer screening recommendations (Coughlin et al., 2003; Mandelblatt et al., 1999; Ramirez et al., 2000; Suarez et al., 1997); similarly Scarinci et al. (2003) reported that Hispanic women who had less education were found to have lower use of cervical cancer screening.

Cultural beliefs.

Beliefs about cervical cancer among Hispanic women were associated with promiscuous sexual activity, such as many sexual partners at the same time and immoral behavior (Chavez, McMullin, Mishra, & Hubbell, 2001; Guilfoyle et al., 2007; McMullin et al., 2005; Vanslyke et al., 2008). Hispanic women, especially immigrants, believe that cervical cancer is caused by physical stress, birth control pills, and trauma such as

abortions or rough sex (Chavez et al., 2001; Chavez et al., 1997), sexuality is considered a very private matter (Hubbell et al., 1996), and many Hispanic women may be reluctant to talk about it, especially if there is a lack of trust between the patient and the provider (Guilfoyle et al., 2007; McMullin et al., 2005; Pinzon-Perez et al., 2005; Vanslyke et al., 2008). Fear of cancer, or, as it has been termed in the literature, *fatalism*, or preferring not to know a cancer diagnosis, was another recurring theme among cultural Hispanic beliefs noted in several articles (Arredondo et al., 2008; Behbakht et al., 2004; Chavez et al., 1997; Guilfoyle et al., 2007; Powe & Finnie, 2003). This concept is illustrated in a recent ethnographic study conducted in the Texas-Mexico border to explore HPV cultural beliefs, knowledge and attitudes of Hispanic men and women. A participant expressing fatalistic views is quoted as declaring, "I hear cancer, I hear death" (Fernandez et al., 2009, p. 614). Authors concluded that many women believed that a diagnosis of HPV equaled cervical cancer and death, which is consistent with other studies about fatalism views and cancer of Hispanic women (Fernandez et al., 2009). In addition, in a mixed methods study, Chavez et al. (1997) reported that Latinas held more fatalistic views in regard to cervical cancer and were less likely to have had a Pap smear within the last three years as compared to non-Hispanic white women. These views may represent additional barriers to cervical cancer screening among this population.

Limited English proficiency among Hispanics has also been reported as a barrier or risk to screening practices (De Alba et al., 2004; Fernandez & Morales, 2007). In addition, several studies have found that English proficiency among Hispanic women is

related to higher rates of cervical cancer screening as compared to those with low English proficiency (Arredondo et al., 2005; De Alba et al., 2004; Jacobs et al., 2005). Furthermore, Hispanic women who were less acculturated as measured by language spoken at home were found to have decreased use of Pap smear screening (Shah et al., 2005). In contrast, Abriado-Lanza, Chao, and Gates (2005) found that acculturation did not predict recent Pap smear screening (odds ratio 1.38, 95% confidence, CI=0.99). Cultural beliefs are important influences on Hispanic women's behavior related to cervical cancer screening (Chavez et al., 2001).

Age.

In the studies reviewed, participants' ages varied from 18 years to 83. Few studies specifically addressed older Hispanic/Latina women. Of those including older Hispanic women, data indicated that they were less knowledgeable about cervical cancer than younger cohorts and were the least likely to be screened for cervical cancer (Coughlin et al., 2003; Mandelblatt et al., 1999; Ramirez et al., 2000; Suarez et al., 1997). Three studies addressed women older than 40 and found that Mexican ethnicity and older age were associated with lower rates of Pap smear screening (Fernández-Esquer, Espinoza, Ramirez, & McAlister, 2003; Peragallo et al., 1997; Randolph, Freeman, & Freeman, 2002). In particular, one study conducted in Texas reported that 64.1% of older Mexican American women had a Pap smear in the last three years, which is below the 90% national goal (Randolph et al., 2002). Culture, beliefs, values, language, and age are all factors contributing to decreased use of cervical cancer screening among Hispanic/Latina women.

Health care insurance.

Having health insurance and a regular satisfactory source of care has been shown to improve cancer-screening practices among Hispanic women (Bazargan, Barzargan, Farooq, & Baker, 2004; Bordes, Warner, & Sutkin, 2003; Carrasquillo & Pati, 2004; Fernandez-Esquer & Cardenaz-Turanzas, 2004; Goel et al., 2003, Nash, Chan, Horowitz, & Vlahov, 2007; Owusu et al., 2005; Rodriguez, Ward, & Perez-Stable, 2005; Sambamoorthi & McAlpine, 2003; Zambrana, Breen, Fox, & Gutierrez-Mohamed, 1999). In addition, Goel et al. (2003), in a cross-sectional study with a large sample size of 32,440 respondents of which 5,155 were Hispanic, reported that foreign-born Hispanics were less likely to receive cervical cancer screening as compared to U.S.-born Hispanic women. However, after adjusting for access to care, the differences were not statistically significant (AOR 0.89; 95% CI, 0.70 to 1.114). The authors concluded that one of the barriers for foreign-born Hispanics is lack of access to care; therefore, improving health care access may improve screening among this population. In addition, Satcher (2000) reported that many women needing screening services go unscreened due to lack of insurance, many of whom are Hispanic, increasing their mortality rates; therefore, it is imperative to continue to support programs for uninsured women such as the National Breast and Cervical Cancer Early Detection Program. As one variable in a complex puzzle, access to care improves cervical cancer screening rates, improves quality of life, and decreases mortality rates among Hispanic women.

In addition, cancer education has been correlated with increased rates of Pap smear screening (Buki, Jamison, Anderson, & Cuadra, 2007). Educational programs

targeted to Hispanic women included the use of *promotoras* or *consejeras* (lay bilingual health workers) to conduct the educational program sessions. In all instances where *promotoras* or *consejeras* were employed, knowledge and cancer screening improved among the participants with an average age of 35, and it was reported as an effective method to educate Hispanic women (Hansen et al., 2005; Larkey, 2006; Navarro, Raman, McNicholas, & Loza, 2007; Navarro et al., 1998). Mass media campaigns and a combination of informational approaches have also been used with some success with younger groups of women (Fernández-Esquer et al., 2003; Warren, Londono, Wessel, & Warren, 2006). Although increased rates of cervical cancer screening among younger groups of women has been reported, little information is available regarding effective health education and communication methods for older women.

Although it is important to assess how all the above variables influenced cervical cancer screening behavior, health literacy was not evaluated, and few studies specifically addressed older (> 40 years) women. Additional studies aimed at older (>50 years) women of Mexican American origin are needed in order to understand and address this health care disparity.

Health literacy.

Health literacy is defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate heath decisions" (Ratzan & Parker, 2000, p. v). The above definition is widely used in the literature and adopted by the Institute of Medicine in 2004. Health literacy is an imperative skill set necessary for health maintenance and prevention

(Ratzan & Parker, 2000). Similarly, Zarcadoolas et al (2005) define health literacy as **"**the wide range of skills, and competencies that people develop to seek out, comprehend, evaluate and use health information and concepts to make informed choices, reduce health risks and increase quality of life"(p. 196).

Inadequate health literacy has been predominantly found among older adults, nonwhite, lower income, and those with a lower educational attainment (Baker et al., 2004; Gazmararian et al., 1999). Functional health literacy among older adults has been reported to decline with age, for every year of age the S-TOFHLA (health literacy measurement) score declined by 0.9 ($p < .001$) after adjusting for other variables including performance on the Mini Mental State Examination (MMSE) (Baker, Gazmararian, Sudano, & Patterson, 2000). Similarly in a systematic review of the literature, Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, and Rudd (2005) reported that age, ethnicity, level of education, and Spanish language were associated with low health literacy.

In a recent literature review, authors concluded that patients with low literacy had worse health outcomes and were 1.5 to 3 times more likely to experience poor outcomes (DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004). Similarly Cho, Lee, Arozullah, and Crittenden (2008) reported that health literacy had a direct effect on health outcomes and concluded that improving health literacy may be the best approach to improving health outcomes among the elderly. Low health literacy has also been reported to be a predictor of self-reported poor health (Baker, Parker, Williams, Clark, & Nurss, 1997; Sudore et al., 2006), worse physical function, worse mental health, and more difficulty

with activities of daily living as compared to those with adequate health literacy (Wolf, Gazmararian, & Baker, 2005). In addition it has also been reported that individuals with low literacy are more likely to experience a hospital admission (Baker et al., 2002) and incur higher Emergency Room costs (Howard, Gazmararian, & Parker, 2005).

In a prospective cohort study, inadequate health literacy was found to have a strong association with mortality (18.9% vs. 39.4%) after adjusting for socio-demographic factors and chronic disease. Inadequate health literacy was also associated with cause-specific mortality, for example; mortality related to cardiovascular disease was 19% for those with inadequate health literacy vs. 7.9% for those with adequate health literacy. Similarly, mortality related to cancer was 8.8% for those with inadequate health literacy vs. 5.8% for those with adequate literacy (Baker et al., 2007). In a 5-year prospective study, Sudore et al. (2006) reported that limited health literacy was associated with a two-fold increase in mortality (19.7% vs. 10.6%). Poor health outcomes and higher mortality rates could be related to less knowledge of the need for preventive care.

Preventive care and health literacy

Low health literacy has been associated with underutilization of preventive care services including influenza and pneumococcal vaccine, colorectal cancer screening, mammography and Papanicolaou smear (Bennett, Chen, Soroui, & White, 2009; Cho et al., 2008; Guerra, Dominguez, & Shea, 2005; Guerra, Krumholz, & Shea, 2005; Scott et al., 2002; White, Chen, & Atchison, 2008). A recent cross-sectional study was conducted to identify the relationship between health literacy and preventive health practices. Authors reported that low health literacy was associated with decreased use of seven of

nine preventive health services, including mammograms, and was associated with older age (White et al., 2008). In contrast higher heath literacy was related to having had a Pap smear (White et al. 2008). Similarly Scott et al. (2002) reported that women with inadequate health literacy were more likely never to have had a Papanicolaou (10% vs. 5%) and not to have had a mammogram (24% vs. 17%). In addition, Davis et al. (1996) reported that women with lower reading levels lacked information and exhibited more negative attitudes such as embarrassment toward mammography.

Guerra, Krumholz et al. (2005) explored the association between functional health literacy and mammography among Latinas and concluded that functional health literacy was associated with greater odds of having a mammogram. It is important to note that in this sample (*N*=97) 70% of Latinas scored inadequate or marginal health literacy on the S-TOFHLA. These findings are congruent with other studies; therefore, the authors recommend further research to increase rates of screening among low health literate populations. In contrast, Bennett et al. (2009) reported that Latinas were more likely to report a mammogram compared to non-Hispanic white women (75% vs. 65%); however, they reported an association between increased health literacy and receiving preventive health services such as influenza vaccine, mammography and dental care. Notably few studies have explored the association between preventive health practices and health literacy among Hispanics.

Health Literacy and Hispanics

Spanish-speaking Hispanics consistently score lower or inadequate on health literacy tests compared to non-Hispanic whites (Brice et al., 2008; Britigan, Muran, &

Rojas-Guyler, 2009; Sarkar et al., 2010). Furthermore, 17.2% of English-speaking Hispanics had an inadequate health literacy score and 10% had a marginal score on the S-TOFHLA (Zun, Sadoun, & LaVonne, 2006). In addition, in a survey used to characterize a patient population, Sarfaty, Turner, and Damotta (2005) reported that 60% of Hispanics had less than a forth grade education and 19% had an education level of fifth to eight grade, for a total of 79% with less than eighth grade education.

Interventions aimed at improving the health literacy of Hispanic patients are limited, but they include a pilot study to improve HIV health literacy (Van Servellen et al., 2005), evaluating the learning needs and educational materials available for female Mexican American caregivers (Cagel & Wells, 2009), use of MedlinePlus through *promotoras* (Olney, Warner, Reyna, Wood, & Siegel, 2007), and use of an internet portal for diabetic patients (Sarkar et al., 2010). A randomized control trial was conducted by van Servellen et al. (2005) to assess the impact and adherence of HIV medications in Spanish-speaking Latinos: 42 participants were enrolled in the pilot intervention and 43 participants were enrolled in the comparison group. One of the study's goals was to improve HIV health literacy. Data were collected from chart reviews and face-to-face interviews at baseline and at six weeks. HIV health literacy was measured with a Modified REALM test as well as a 17-item scale to evaluate disease knowledge and misconceptions. The authors found that there was a significant difference in HIV knowledge base and HIV health literacy for the intervention group as well as increased recognition of HIV terms compared to the group receiving standard care. Medication

adherence also improved for those enrolled in the pilot group intervention (van Servellen et al.).

Koskan, Friedman, and Messias (2010) conducted a literature review to examine health literacy among U.S. Hispanics and found a total of 27 studies; of those, only 10 focused on Hispanics. They also found that while many studies focused on diseases and health literacy (*n*=15), few focused on women (*n*=3). The authors concluded that Spanish-speaking foreign-born participants have the lowest health literacy and recommended additional research with specific Hispanic subgroups. Furthermore, a systematic review from the Agency for Healthcare Research and Quality (AHRQ, 2004) concluded that there were insufficient data available to evaluate "whether health literacy has a differential effect in various subgroups of the population" (Berkman et al., 2011, p. 224) and additional research is needed related to health disparities among ethnic minorities, the elderly, and women (Berkman et al., 2011).

Health Literacy and Hispanic Women

Studies related to health literacy and gender, report mixed findings on performance scores of health literacy tests. A recent study conducted by Aguirre, Ebrahim, and Shea (2005) to test the psychometric properties of the Short version of the Test of Functional Heath Literacy (S-TOFHLA) in English and Spanish, showed that women scored better than men although Gazmararian et al. (1999) reported no difference in the scores of health literacy tests between men and women. Both studies, Aguirre et al. and Gazmararian et al., reported large sample sizes (*n* = 2,370 and *n* = 3,260, respectively).

Inadequate health literacy among Hispanic women has been associated with Mexican ethnicity, less than high school education, and older age (Bennett, Culhane, & Elo, 2007; Guerra, Krumholz et al., 2005) In addition, authors report that pregnant Latina women with limited English proficiency and those with inadequate health literacy are two times more likely to experience depressive symptoms when compared to women with adequate health literacy (Bennett et al., 2007). Inadequate health literacy among Hispanic women has been associated with poor knowledge of frequency of mammography (Guerra, Krumholz et al., 2005), poor decision outcomes (Hawley et al., 2008), and poor patient-physician communication, and, Spanish speaking participants especially had the worst patient-physician communication (Sudore et al., 2009). Although authors (Hawley et al., 2008; Sudore et al., 2009) concluded that providers must take into consideration health literacy, ethnicity, language, and communication type during the health care encounter, few studies addressed health literacy needs of Hispanic women with regard to cervical cancer screening.

Health Literacy, Cervical Cancer Screening, and Hispanic Women

To date only one non-experimental study has evaluated the relationship between health literacy and cervical cancer screening among Hispanic women (Garbers & Chiasson, 2004), and one has evaluated the relationship of health literacy and cervical cancer screening among a multiethnic cohort (Lindau et al., 2002). Researchers have found a significant relationship between low health literacy and low Pap smear screening (Garbers & Chiasson, 2004; Lindau et al., 2002; Scott et al., 2002).

The study conducted by Garbers and Chiasson (2004) examined the association between functional health literacy and Pap smear screening in Spanish among Hispanic women older than 40 years old. The authors found that women with inadequate health literacy were less likely to have ever had a Pap smear (OR, 0.12; 95% [CI], 0.04-0.37) and were 16.7 times less likely to have had a Pap test compared with those with adequate or marginal health literacy. In this sample (n=205), 30% of participants had inadequate health literacy, 19% had marginal health literacy, and only three women knew that a Pap test was performed to detect cervical cancer. It was found that after controlling for other factors such as age, insurance, education, and ethnicity, health literacy was an independent factor and had a strong inverse relationship to having a Pap test (Gabers & Chiasson).

While Gabers and Chiasson (2004) studied Spanish-speaking Hispanic women, Lindau et al. (2002) focused on a multiethnic cohort of English-speaking women older than 18 years of age, including African American (58%), Hispanic (18%), non-Hispanic white (15%), and other (10%). In this sample (n = 529), 1 in 10 participants had inadequate health literacy, one third had marginal health literacy, only five women had had a Pap smear, and only 13% could articulate the purpose of the Pap smear. Health literacy was a predictor of health behavior including cervical cancer screening; however, ethnicity was not a significant predictor of cervical cancer screening practices in this sample.

It is important to note that in these studies (Gabers & Chiasson, 2004; Lindau et al., 2002) the instruments used to measure health literacy were diverse, making

comparisons more difficult. One study used the Spanish version of the Test of Functional Literacy for Adults (TOFHLA) (Garbers & Chiasson, 2004) and one used the Rapid Estimate of Adult Literacy in Medicine (REALM) (Lindau et al., 2002). In addition, only the study conducted by Gabers and Chiasson (2004) focused on Hispanic older women (> 40 years old).

A recent literature review to evaluate common tools used in the assessment of health literacy included the TOFHLA and the S-TOFHLA, a comprehension test, and the REALM, or word recognition test. Authors concluded that the REALM can be used for screening health literacy; however, it may not be accurate and should not be used for Spanish-speaking individuals. Comprehension tests such as the TOFHLA or S-TOFLA require more time to administer but could be used for Spanish-speaking individuals. Authors recommend that semi-structured interviews may be more helpful to for those with low literacy (Friedman & Hoffman-Goetz, 2006).

Summary

Death from cervical cancer is preventable if women are properly screened. While there seems to be adequate amounts of research related to Hispanic women's knowledge and beliefs about cervical cancer and Pap smear screening, there is little information about their health literacy and its relationship to cervical cancer screening. Barriers to cervical cancer screening among Hispanic/Latino women have been identified, including lack of knowledge, cultural beliefs, health care barriers, language, and low health literacy regarding cervical cancer screening. This researcher noted that the majority (88%, 47/53) of studies related to cervical cancer screening and Hispanic women were conducted in

English and Spanish; however, a sharp contrast was noted in the health literacy studies in which only 2% (6/30) were conducted in English and Spanish, leaving a large gap in health literacy literature. In addition a significant number of health literacy studies (33%, 9/30) reviewed were from the same sample data set described as non-Hispanic white (76%), female (57.4%), high school diploma (33.6%) and (30.7%) more than high school diploma, Hispanic (11.2%). However, these studies may not be a typical sample (Baker et al., 2000; Baker et al., 2002, 2004; Baker et al., 2007; Gazmararian et al., 1999; Gazmararian, Williams, Peel, & Baker, 2003; Howard et al., 2005; Scott et al., 2002; Wolf et al., 2005).

While the majority of the studies used standardized and validated tests to measure health literacy including The Test of Functional Health Literacy in Adults (Baker et al., 1997; Brice et al., 2008; Williams, Baker, Parker, & Nurss, 1998; Williams et al., 1995), The Short version of the Test of Functional Health Literacy in Adults (Aguirre et al., 2005; Baker et al., 2000; Baker et al., 2002; Baker et al., 2004; Baker et al., 2007; Bennett et al., 2007; Britigan et al., 2009; Cho et al., 2008; Gazmararian et al., 1999; Green, Hibbard, & Tusler, 2005; Guerra, Krumholz et al., 2005; Hibbard, Peters, Dixon, & Tusler, 2006; Howard et al., 2005; Scott et al., 2002; Wolf et al., 2005; Zun et al., 2006), and the Rapid Estimate of Adult Literacy in Medicine (REALM) (Arnold et al., 2001; Davis et al., 1996; Sudore et al., 2006). Other researchers (Hawley et al., 2008; Leyva, Sharif, & Ozuah, 2005; Sarfaty et al., 2005) developed their own measurement tools; still others did not use a health literacy test (Cagel & Wells, 2009; Hinojosa et al.,

2010; Hunter, 2005; Olney et al., 2007; Sarkar et al., 2010). These variables make conclusions and comparisons among studies difficult.

Educational programs have been evaluated, including the use of different multimedia programs and the use of *promotoras or consejeras* (Hansen et al, 2005; Larkey, 2006; Navarro et al., 2007; Navarro et al., (1998). The aforementioned programs included women age 18 and older but did not specifically addressed older women's concerns. To date, no studies have been published evaluating the health literacy needs of older women of Mexican American origin. Little is known about the influence of knowledge, beliefs, and preferred education/communication styles for specific Hispanic/Latino subgroups, including older women of Mexican American origin. "Lives are lived and told in relation to other lives and in a historical and cultural context" (Sandelowski, 1997, pp. 127-128). Therefore, qualitative methods are best suited to explore age, cultural, and linguistic differences that may exist among this population. The additional knowledge gained may be used to improve patient communication and cervical cancer screening educational strategies to improve health outcomes of this vulnerable population. Few studies have included health literacy as a variable to cervical cancer screening. The present study will address the lack of information available regarding the health literacy needs of this vulnerable group of women.

Chapter Three

Methods

Introduction

Qualitative descriptive designs have been used to explain population characteristics and to answer the questions of "the *who*, *what* and *where* of events or experiences" (Sandelowski, 2000, p. 337; Sandelowski, 2009; Wood & Ross-Kerr, 2006). Sandelowski (2000) proposed that qualitative research will "tend to draw from the general tenets of naturalistic inquiry" (p. 337). Since there is a paucity of research regarding the health literacy experiences and information-seeking behaviors of English and/or Spanish speaking older women of Mexican American ancestry specific to cervical cancer screening, this qualitative descriptive study is well suited to answer the proposed research question.

Assumptions of Naturalistic Inquiry

The following assumptions are summarized from Erlandson, Harris, Skipper, and Allen (1993) and Lincoln and Guba (1985).

1. There are multiple realities that cannot be resolved through rational process.
2. Convergence comes when all pieces of reality are seen.
3. An understanding can begin with a holistic view of a piece from the whole.
4. Qualitative inquiry extrapolates deep understanding of the phenomenon by collecting thick data.

5. The primary instrument is the researcher.
6. Researcher objectivity is an illusion. There is mutual influence between the researcher and the participants. The researcher must find ways to control for bias.
7. The primary instrument is the researcher.
8. Tacit knowledge and propositional knowledge are treated equally.
9. The relationship between language and experience is important. The researcher must have similar constructions in order to communicate with the participants.
10. Timing cannot be predicted, as events have not occurred.

Research Design

Qualitative descriptive studies can involve interviews of subjects either individually or in focus groups using open-ended questions (Morgan, 1998a; Sandelowski, 2000; Verhonick, 1971). Focus groups can be used to obtain exploratory information about a phenomenon and gather a greater perspective of the issue (Frey & Fontana, 1991; Sandelowski, 2000). Focus group methods have been used to develop educational materials that account for the social and cultural circumstances of low literate populations, provide in-depth knowledge of specific populations (Lasch et al., 2000), help understand different aspects of the group that go past language and ethnicity (Morgan, 1998a), and add a voice to underrepresented populations in the development of new interventions (Espocito, 2001), including a videotape intervention for HIV-positive women (Murdaugh & Russell, 2000) and cancer education materials in multicultural

groups (Wilkes, Montouri, Chew, Leonard, & Hilton, 2000). In addition, they are well suited to older Hispanic women since the focus group interview takes into account the oral traditions and social norms of the Hispanic culture (Saint-Germain, Bassford, & Montano, 1993). The combination of focus groups and individual interviews adds strength (Morgan, 1997) and greater description of the phenomenon of study (Lambert & Loiselle, 2008) since both techniques balance each other (Morgan, 1997).

The strengths of focus group methods include "(1) exploration and discovery, (2) context and depth, and (3) interpretation" (Morgan, 1998a, p. 12). This method is intended to produce a large amount of rich data in a short period of time through the group discussion (Morgan, 1998a). Communication between researcher and participants is essential since this is a process of sharing and comparing ideas and thoughts (Morgan, 1998a). Focus groups provide a large amount of interaction related to one topic, are limited to self-report data, and verbal behavior. Group discussions provide similarities and differences regarding the topic, rely on group interaction, and have been used to address difficult topics, including family planning and sexually transmitted diseases. The data from focus groups come from what participants say during the group discussion (Morgan, 1997, 1998a).

Individual interviews are often combined with focus group data; this is done fairly easily since both are qualitative techniques (Morgan, 1996). Additional material can be gathered from individual interviews to help "broaden the depth" (Munhall, 2007, p. 187) and add richness to the study. Key informants comprise one of the most common sources of data. The researcher often selects key informants purposefully many times based on

roles, knowledge, and experience that will help to understand the problem and/or answer the research question (Creswell, 2003; Curry, Shield, & Wetle, 2006; Polit & Beck, 2004). In-depth individual interviews often follow focus group discussion; this combination method first discovers a broad range of ideas followed by obtaining more specific information as needed (Morgan, 1996).

Setting.

Texas has a rich Spanish and Mexican history from 1540 with the expansion of the Spanish Crown. Conqueror Francisco Vasquez de Coronado came to Texas when Mexico acquired independence from Spain, and Texas became a part of the state of Coahuila. Finally in 1842 with the treaty of Guadalupe-Hidalgo, Mexican families living in Texas were granted U.S. citizenship and land titles confirmed. The word *Tejas* or *friends* derives from old Spanish; the *j* sound was substituted with the *x* sound and, therefore, the name Texas (Fehrenbach, 2000). This rich history provides an appropriate setting for the present study.

The census reports of Mexico in 1820 show that 18% of the population was pure European, 22% was mixed or mestizo, and 60%, Indian (Fehrenbach, 2000). The present day population in Bexar County, location of this study, according to the U.S. Census Bureau (2009) is 57.9% Hispanic (of any race), 31.8% Non-Hispanic white, 1.1% Indian, and 7.7% Black. This study was conducted in a community center with similar population representation. South Texas provided an ideal setting for conducting this study due to its original roots in Mexican history, culture, and language, with 43% of the population speaking a language other than English at home (U.S. Census Bureau, 2009).

The community center's mission is to provide social, psychological, and physiological well-being to older citizens. Some of the services provided by the center include nutrition, exercise, recreation, and transportation to older citizens and their spouses. The center's population mirrors that of the community. Permission from the community center's director was obtained and key personnel were identified, including the Manager of Operations. They provided support to conduct focus groups including scheduling the conference room, helping with recruitment of participants by disseminating flyers, publishing an article in their newsletter about cervical cancer prevention, and giving verbal information about the study.

Sample and sampling procedures.

After obtaining Institutional Review Board (IRB) approval from The University of Texas at Austin (Appendix C), a purposive convenience sample was recruited to participate in the focus group discussion and individual interviews. In addition, some participants were recruited through snowball sampling. Purposive sampling is preferred in naturalistic inquiry and focus group research design; participants are selected because they have experienced the phenomenon under study (Erlandson et al., 1993; Morgan, 1998b). This sampling method was used to increase the depth of discovery and patterns in the data (Erlandson et al., 1993; Morgan, 1998b; Sandelowski, 2000). Purposive sampling includes the assumption that the researcher must select who and what to study and who and what not to study (Erlandson et al., 1993). Some participants were recruited through snowball sampling in which participants recommended the study to others (Richards & Morse, 2007). In order to facilitate group discussion, participants of similar

demographic backgrounds were selected by gender, age, and ethnicity (Morgan, 1998b). Careful selection of participants minimized bias (Morgan, 1998b). For the purposes of this study, the sample inclusion criteria for both focus group participants and individual interviews were:

1. Women of Mexican American origin by self-report.
2. Able to communicate in English or Spanish.
3. Age 50 and older.
4. Community-dwelling women without major impairments (cognitive, visual, verbal).
5. Negative history of cancer.
6. Intact uterus.

Segmentation was used to vary the composition of the groups; this approach "builds a comparative dimension" (Morgan, 1996; p. 143) for the research and data analysis as well as helps to make the groups homogenous (Morgan, 1996). Potential participants were screened via telephone survey or in person, and the findings were used to segment the group participants by language spoken, either English or Spanish, and cervical cancer screening (> 3years).

Problems such as cognition, vision, and hearing impairments may affect reading comprehension and, therefore, functional health literacy in older adults (Baker et al., 2000). The authors reported that "mental health and visual acuity were positively associated with functional health literacy" (Baker et al., 2000, p. S371). Research studies related to health literacy and older adults have excluded participants based on clinical

dementia, performance of basic activities of daily living (Sudore et al., 2006), mental competence, visual and hearing acuity (Cho et al., 2008), and is a disadvantage of focus group design since some individuals are excluded from participation (Basch, 1987). Therefore, participants were screened for major cognitive impairments and vision and hearing impairments not corrected by glasses or hearing aids by asking the following questions:

1. Do you live at home?
2. Does anyone notice that you have a problem with your memory?
3. Has anyone ever told you that you have a problem with your memory?
4. Has a doctor ever told you that you have memory problems?
5. Do you have any vision problems?
6. Do you wear glasses?
    a. If yes, follow up question: Is your vision corrected with glasses?
7. Do you have any hearing problems?
8. Do you wear a hearing aid?
    a. If yes, follow-up question: Is your hearing corrected with the hearing aid?
9. Are you able to walk a flight of stairs?

Participants were recruited from two community centers in South Texas. Participants were recruited by posting flyers, and those interested used a sign up sheet at the front desk of the community centers. In addition, senior center staff introduced researcher to diverse senior center classes where attendees were asked if they wished to

participate in the study. If they indicated a wish to participate, the researcher met with the attendees referred by the community center to answer questions regarding the study. Interested participants were invited to participate in either focus group discussion or individual interview until the groups were formed.

Five focus groups of three to eight participants each were conducted; group discussion lasted for 45 to 90 minutes. In addition, seven individual interviews were conducted lasting from approximately 45 to 90 minutes each. Data theoretical saturation was achieved as no new information was discussed by participants. Saturation typically occurs after three to five focus groups (Morgan, 1998b). Focus groups were conducted in a meeting room in the community center. Similarly, individual interviews were conducted in a private and comfortable room in the community center. Participants received a $30.00 gift certificate for their time and participation. A total of 30 women agreed to participate in the study, and data saturation was reached.

Human Subjects Protection

Protection of human subjects is guided by several principles: autonomy, beneficence, non-maleficence, and social justice. Autonomy refers to the individuals' right to decide if they wish to participate in a research study. Beneficence or *doing good* (developing new preventive interventions) is considered to add benefit to the patients. Non-maleficence or *do no harm* was projected because the study did not pose direct harm to the participants as a research goal. Social justice is defined as the right to be represented in the sample (Wood & Ross-Kerr, 2006). In the present study, males were not included because the focus of the study was on cervical cancer screening.

Conducting a study with minimal risk to participants also preserves the principle of non-maleficence. Although minimal potential risks were anticipated, discussion is warranted. Fatigue of participants was a potential risk that was minimized by limiting the focus group session to no more than 90 minutes. Another potential risk is loss of anonymity, which was minimized by using pseudonyms. Autonomy was preserved; all participants were older than 18 years and were provided with an informed consent form before data were collected. Participants were able to withdraw from the study at any point. All answers were voluntary. The consent form was explained and read aloud to all participants in their preferred language. The University of Texas at Austin Institutional Review Board (IRB) granted a Waiver of Documentation of Consent.

Participants' identity and confidentiality were protected. The researcher did not collect names, addresses, telephone numbers, or social security numbers. Interviews were audio recorded and transcribed word-for-word by a professional transcriber. Once transcription was complete, only the researcher and committee members had access to the recording, and the data are scheduled for destruction after completion of the project. Transcription data did not include any identifying information. During discussion, participants were given a pseudonym. At the beginning of the focus group, the researcher provided the opportunity for safeguarding information within the group; all agreed to group confidentiality and to avoid over-disclosure. Participants were instructed to avoid saying something they might regret later; stressful situations did not occur. There were no further questions from participants at the end of the interviews and referrals to community agencies were not needed.

The principle of beneficence was preserved; the information obtained may be used to have a better understanding of the health literacy needs of older women of Mexican American ancestry. In doing so, new educational technologies and better communication strategies may be developed to increase cervical cancer screening and decrease mortality rates among this group of women.

Data Collection, Instruments, and Procedures

Data collection to meet the objectives of this study included demographic data. The demographic information collected included (a) age, (b) marital status, (c) education level, (d) preferred language, (e) ethnicity, (f) income, (g) zip code, and (h) approximate date of last Pap smear (see Appendix D). All data collection was referenced with a pseudonym and number which participants obtained from a predetermined number of cards. All data collection was transported safely and locked in the researcher's office. Furthermore, reports included group demographics without pseudonyms further providing anonymity (Richards & Morse, 2007).

Focus groups.

Focus groups were conducted using semi-structured questions. Focus groups and individual interviews took place in a private conference room designated by the community center with ample space and comfortable seating. Interviews were conducted in English or Spanish. All forms were translated from English to Spanish. The assistant moderator, an experienced bilingual, bicultural researcher, used probes such as "*I understand you said*…" to further elaborate, summarized the discussion, observed group dynamics, and took notes. Focus groups started with "grand-tour questions," which

helped participants relax and get used to talking to the interviewer (Lincoln & Guba, 1985), followed by semi-structured questions, which became more specific as the discussion proceeded following a moderator guide (Appendix E, English; Appendix F, Spanish). The use of probes when needed included silence, "uh-huh," or asking follow up questions such as "did I understand you correctly when you said…" (Lincoln & Guba, 1985). Grand tour and semi-structured questions were developed following Zarcadoolas et al.'s (2005) health literacy model. The moderator guide using *open-ended key questions* was followed in English and Spanish.

Fundamental literacy was partially assessed using a screening literacy tool, *The Newest Vital Sign* (Weiss et al., 2005). English (Appendix G) and Spanish (Appendix H) versions were available. Permission for use was obtained (see Appendix I). A health information scenario was given to participants followed by questions related to the scenario; this was a 6-item test and took approximately three minutes to administer. Scores are grouped into three categories 0-1, 2-3, 4-6; scores >4 were considered to have adequate literacy vs. those who scored <4, who were considered to possibly have limited literacy. The sensitivity was 100% and the specificity 64% for scores <4. The internal consistency (Cronbach $\alpha = 0.76$) and correlation with the TOFHLA, ($r = 0.59$, $P =< .001$).

Science literacy was assessed using the following questions:

1. What tests do you think women need to get to protect their health?
2. What do you think of when you hear the term Pap smear?
3. How often do you think someone should have a Pap smear?
4. What do you think prevents cervical cancer?

5. What do you think of when you hear the term cervical cancer?
6. What do you think of when you hear the term Human Pappilloma Virus (HPV)?

Questions in Spanish

1. *¿Qué tipo de exámenes son necesarios para que las mujeres protejan a su salud?*
2. *¿En qué piensan cuando oye la palabra Papanicolaou?*
3. *¿Qué tan seguido piensan una persona necesita hacerse un examen de Papanicolaou?*
4. *¿Qué cree usted previene el cáncer cervicouterino?*
5. *¿En qué piensa usted cuando oye el termino cáncer del cervicouterino?*
6. *¿En qué piensan cuando oye el termino Virus de Papiloma Humano?*

The following questions examined Civic literacy:

1. Where do you obtain information about Pap smears?
2. How would you like to receive this information?
3. What do you like or dislike about the information you have received?

Questions in Spanish

1. *¿Donde obtiene información acerca del la prueba de Papanicolaou?*
2. *¿Cómo le gustaría recibir este tipo de información?*
3. *¿Qué es lo que le gusta o disgusta acerca de la información que ha recibido*?

Media literacy was determined after presenting two Internet brochures followed by the following questions:

1. What do you like about the information presented?
2. What you do not like?
3. What is helpful?
4. What is not helpful?
5. What would you change?
6. Do you think the information presented would help you or someone else obtain a Pap smear?

Questions in Spanish

1. *¿Donde reciben información acerca del la prueba de Papanicolaou?*
2. *¿Cómo prefieren recibir esta información?*
3. *¿Qué es lo que le gusta o no les gustan de la información que ha recibido?*
4. *¿Usted cree que la información que hemos presentado le ayudaría a usted o alguna otra persona a obtener el Papanicolaou?*

Cultural literacy was tested through the responses to these questions:

1. What is the general attitude among your friends and family regarding Pap smears?
2. Tell us about how your culture or beliefs affect your views on Pap smears?
3. Are there any religious or cultural pressures, which make it hard to obtain a Pap smear?

4. Did your mother talked to you about Pap smears?
5. Would you talk to younger family members (daughters or granddaughters) about pap smears?
6. What advice would you give other women about Pap smears?

Questions in Spanish

1. *¿Qué tipo de actitudes tienen sus amigas o familiares acerca del Papanicolaou?*
2. *¿Platíquenos como su cultura o creencias refleja sus opiniones acerca del Papanicolaou?*
3. *¿Hay algo cultural o religioso que impide a una persona a obtener la prueba Papanicolaou?*
4. *¿Sus madres les platicaron acerca de los Papanicolaou?*
5. *¿Usted podría hablar con miembros de su familia mas' jóvenes como sus hijas o nietas acerca de el examen de Papanicolaou?*
6. *¿Que consejos podría usted dar o otras mujeres acerca del Papanicolaou?*

At the end of each focus group session, a summary themes or ideas was presented to the group by the assistant moderator (Krueger, 1998b), and the participants were asked if there was anything to add to the comments. This summary helped validate the constructs or member-check; new information was added; and respondents had a right to withdraw (Lincoln & Guba, 1985). After the summary, a final question was asked, "Have we missed anything?" (Kruger, 1998b; p. 31) and/or "Any other thoughts that may have occurred to you?" (Morgan, 1997, p. 51).

The moderator and assistant moderator in focus groups spoke the language (English/Spanish) of the group fluently. Interpreters in focus groups are not recommended and were not used, adding research value (Kruger, 1998b). All questions were translated into Spanish and presented by bilingual/bicultural moderator. A bilingual/bicultural doctoral prepared nurse was the observer and assisted in the interpretation and meaning of the statements. Observation provided information on the *here and now* which the moderator might have missed, including observation of nonverbal clues, such as body language and/or gestures (Lincoln & Guba, 1985). Moderator and observer had time for debriefing following the focus group session.

Individual interviews.

Individual interviews were conducted in a private comfortable room provided by the community center. Potential participants were invited to participate in either the focus group or individual interview until all groups were formed. Inclusion criteria of key informants included (a) women of Mexican American origin by self-report, (b) able to communicate in English or Spanish, (c) age 50 and older, (d) community-dwelling women without major impairments (cognitive, visual, verbal), (e) negative history of cancer, and (f) with intact uterus.

The individual interviews helped to determine if informants discussed more or different information than in the focus groups, and individual interviews added depth and thickness to the data, which is essential in qualitative research (Rodgers & Cowles, 1993) as an element of triangulation (Lincon & Guba, 1985). In addition to semi-structured questions as previously presented, the researcher used probes to expand on information

such as “could you tell me more” or “you seem to be saying that…” (Lincon & Guba, 1985, p. 271). The researcher/moderator summarized main points at the end of the sessions. This step assisted in member-checks, added additional information, and gave participants the opportunity to withdraw (Lincon & Guba, 1985). The interviews were tape recorded, transcribed word-for-word, and field notes were taken, to include nonverbal modes of communication (Lincon & Guba, 1985) or participant behavior (Rodgers & Cowles, 1993). The researcher/moderator took filed notes of individual interviews. These processes added trustworthiness to the study (Rodgers & Cowles, 1993).

Data Analysis

Qualitative content analysis is the preferred method for analyzing descriptive data (Sandelowski, 2000; Wood & Ross-Kerr, 2006). It is also the preferred method for analyzing focus group using an inductive approach (Sim, 1998). Summarizing the data into categories, describing similarities and differences, and making tabulations of those categories do this; this process of structuring data is called content analysis (Wood & Ross-Kerr, 2006). The processes involve looking for themes in the data and developing frequency tabulation, or how often the response was used (Sandelowski, 2000; Wood & Ross-Kerr, 2006). Major strengths to qualitative content analysis research method include flexibility and deriving further understanding from the data (Elo & Kyngas, 2007; Sandelowski, 2000). Five matrices per interview were developed (Bernard & Ryan, 2010), and matrices were color coded using headings from Zarcadoolas et al.’s (2005) health literacy model. Each matrix was coded and analyzed separately (Miles &

Huberman, 1994); thereafter matrices per category were coded and analyzed together similar to a *meta-matrix* (Miles & Huberman, 1994).

After word-for-word transcription in English and Spanish, the data were read for accuracy. *GMR Transcription* provided transcription services, confidentiality, nondisclosure agreements, and is HIPPA-rule certified. After transcription, the three phases of the Elo and Kyngas (2007) process of inductive content analysis were followed: (a) preparation, (b) organizing, and (c) reporting. The preparation phase began by selecting unit categories as described for the health literacy model of health literacy of Zarcadoolas et al. (2005) following the research question. In the second step, data were organized following a matrix: open coding was used and categories and themes were generated. Themes were grouped under the initial headings from the health literacy model (Zarcadoolas et al., 2005). The process of abstracting themes continued with subthemes. In the third step, themes and subthemes were used to report results.

Trustworthiness.

Focus groups and individual interviews conducted in Spanish were transcribed in Spanish; categories were analyzed in Spanish. The resulting report was translated into English and followed Esposito's (2001) process in which interpreters understand and re-express the meaning in the target language to represent cultural characteristics (Shklarov, 2007). A bilingual/bicultural professional translator, expert researcher and committee member, supported concepts and coding to validate the data. In addition, expert committee members reviewed codes, themes, and definitions for content validity; multiple (5) focus groups supported content validity.

Credibility.

Credibility was established by using the techniques outlined by Lincon and Guba (1985), which made findings more credible: (a) prolonged engagement, (b) persistent observation, and (c) triangulation. Prolonged engagement helped build trust between the researcher and participants in learning the culture (Lincon & Guba). Persistent observation allowed the researcher to identify what was pertinent and what was not and to recognize salient factors (Lincon & Guba). The researcher spent approximately 1-2 hours per month in the community center, meeting, greeting and providing information to those interested. In addition, the researcher observed a variety of classes and activities provided by the community center over a five month period. Another process that added credibility to the study was triangulation, which involved the use of different sources of information including transcriptions, journal, and observation notes (Erlandson et al., 1993; Lincoln & Guba). In addition, committee members, experienced researchers, maintained close communication, which added credibility to the study (Lincon & Guba).

Field notes. The assistant moderator, an experienced, bilingual, bicultural researcher, took group notes. The notes were used to document group dynamics, language, sitting arrangement, participants' quotes, and main ideas (Kruger, 1998). The researcher took field notes of individual interviews, including seating arrangement, observation, language used, and participant quotes. The field notes were coded and analyzed in conjunction with transcripts.

Peer debriefing. Another technique used to add credibility was peer debriefing; this technique helped to keep the researcher "honest" (Lincon & Guba, 1985, p. 308) by

proving a debrifer who questioned the methods, ethical, and legal aspects of the study. Close communication with committee members added credibility to the study. Committee members reached agreement on codes, themes, and translations.

Member check. One of the most important techniques that added credibility to the study was member check, which was conducted at the end of each focus group and individual interview (Lincon & Guba, 1985). Participants were asked at the end of each interview: *is there anything not asked*. In addition, the researcher kept a reflexive journal, or diary, with information about schedules and reasons for methodology and analysis decisions; this added credibility, transferability, dependability, and confirmability to the study (Erlandson et al., 1993).

Transferability.

Using thick description including culture and context with a rich presentation of findings along with quotations and purposive sampling techniques added to the measurement of trustworthiness (Erlandson et al., 1993; Graneheim & Lundman, 2004; Lincoln & Guba, 1985).

Dependability.

According to Lincoln and Guba (1985), dependability "seeks means for taking into account both factors of instability and factors of phenomenal or design-induced change" (p. 299) or how data changes overtime (Graneheim & Lundman, 2004). The researcher had close contact with the committee members to discuss consistency over time. An audit trail was maintained to measure dependability of the study which included (a) raw data, (b) data reduction, (c) data reconstruction including structure of categories,

(d) process notes (journal), (e) materials relating to intentions and disposition (peer debriefing notes), and (f) instrument development information (Erlandson et al., 1993; Lincoln & Guba, pp. 319-320). All data were maintained in a secure area and cross-referenced with supporting data.

Confirmability.

An auditor can confirm findings from the data as findings are traced back from the audit trail. The auditor will make decisions as to logic of findings, proper category labels, and fit of data (Lincoln & Guba, 1985). Close contact was maintained with committee members, via e-mail and/or in person. Committee chair and expert committee members read transcriptions and compared codes with those established by this researcher.

Potential Risks

This study presented minimal risk to the participants; but, given the nature of the research study, potential risks to participants included emotional distress due to disclosure or overdisclosure of information during interviews. No emotional distress was observed during the interviews. Participants were informed at the beginning of the focus group that all answers were voluntary and withdrawal from the study could be made at any time without any repercussion. There are potential risks to participants' confidentiality when conducting focus groups. All members agreed to keep responses and discussion as private information. Pseudonyms were used to preserve participants' confidentiality, and demographic data did not have any identifying information.

Before data collection, a written script was read aloud; all participants received a written copy; and oral informed consent was obtained. The written script in English and Spanish included (a) information about the research study, (b) benefits and risks of participation, (c) confidentiality, (d) contact information, and (e) use of protected health information (PHI). A Waiver of Documentation of Consent was granted by The University of Texas at Austin Institutional Review Board (IRB). Focus groups and individual interviews lasted approximately 45 to 90 minutes. Fatigue during the interviews was not observed. A $30.00 gift card was given to participants for their time after completion of demographic data and literacy tool.

Conclusion

Qualitative descriptive studies are well poised to answer the questions of the study using qualitative content analysis as the preferred method for data analysis. Focus groups are intended to promote discussion, hear participants' ideas, and bring forth an in-depth understanding from the group. Individual interviews can be conducted before and/or after focus groups, which strengthened and added richness to the study. A deeper understanding of ideas can bring better educational tools that health care professionals can use to improve health literacy in older women of Mexican American origin and reduce poor health outcomes by increasing cervical cancer screening.

For those reasons, a qualitative descriptive study was well suited to address the gaps in the literature regarding the health literacy needs of older women of Mexican American ancestry and cervical cancer screening. This study contributes further understanding of the cultural and linguistic health literacy needs from this group of

women, which can then be used to develop better communication between nurses and patients and appropriate patient teaching strategies specifically aimed to close the cervical cancer health disparity in older women of Mexican American ancestry.

Chapter Four

Results

Older Mexican American women have the lowest rate of cervical cancer screening. Low health literacy has been associated with underutilization of preventive health services (White et al., 2008) and may contribute to lower screening rates; therefore, the purpose of the study was to

1. Explore the cervical cancer screening beliefs and practices of English and/or Spanish speaking older women of Mexican American ancestry.

2. Describe the health literacy knowledge and experiences of English and/or Spanish speaking older women of Mexican American ancestry as they relate to cervical cancer screening.

Zarcadoolas et al.'s (2005) health literacy model that describes four main domains: fundamental literacy, science literacy, cultural literacy and civic literacy, was used to guide the study (see also Zarcadoolas, Pleasant, & Greer, 2006).

Research Questions

1. What are the cervical cancer screening beliefs and practices of English and/or Spanish speaking older women of Mexican American ancestry?

2. What are the health literacy knowledge and experiences of English and/or Spanish speaking older women of Mexican American ancestry related to cervical cancer screening.

Sample

Thirty women volunteered to participate in five focus groups composed of three to seven participants. Additionally, seven individual interviews were conducted in English and/or Spanish. Participants were selected from a purposeful convenience sample in which participants met inclusion criteria, volunteered, and had time to participate in the study (Richards & Morse, 2007). Some participants were recruited through snowball sampling in which participants recommended the study to others (Richards & Morse, 2007). Sample inclusion criteria for women's participation in the study was confined to those (a) of Mexican and/or Mexican American ancestry by self-report, (b) older than 50 years, (c) able to speak English and/or Spanish, (d) living in the community, without major visual, hearing, or mental impairments, and (e) negative history of cancer.

Recruitment

Participants were recruited from community senior centers in South Texas. The centers provide a variety of programs to seniors, including a daily lunch, health screenings, and exercise classes such as Aquatics, Tai Chi, and Salsa. Furthermore, the centers provide other educational and recreational activities including computer, music classes, and bingo.

Community Center staff posted flyers (Appendix J) printed on a colorful blue paper and/or provided verbal information about the study to participants at the community senior centers. In addition, community center staff introduced the researcher to senior exercise class participants. Persons interested in learning more about the study

were told to ask the researcher questions about the study, request a flyer, or make contact via telephone.

Setting

Focus groups and individual interviews were conducted at the senior centers in private rooms with tables and chairs easily arranged by the researcher to accommodate the groups or individual interviews. Conference style tables were arranged with, participants seated around the table. A second table was used to welcome participants and to provide refreshments.

Procedures: Focus Groups

At the beginning of the focus groups, participants were encouraged to meet and greet each other, as well as the researchers, to establish a personal relationship. This is important in the Hispanic culture because *personalismo* (personal, friendly), *confianza* (trust), and *simpatía* (polite) are expected mutual values. Similarly, at the end of the focus group, time was allowed for researchers to thank participants for their time with the usual greetings, hugs, handshakes, and pleasant conversation expected in Hispanic culture. Tape recorders were placed in the center of the tables. A second moderator, an experienced bilingual and bicultural qualitative researcher, assisted with note taking, observed group dynamics and group debriefing.

After an initial welcome, introductions were made and informed consent was obtained. The purpose of study and focus group rules were reviewed, including confidentiality of group discussion. Random names in alphabetical order had been prepared on folded cards to facilitate use of pseudonym and introductions. Participants

chose a pseudonym from the group of pre-written name cards, which were then used for introductions around the table.

The researcher was the moderator for the focus groups and began the discussion following the moderator guide (Appendix E): What medical tests do you think are important for women? The moderator guide was developed following Zarcadoolas et al.'s (2005) health literacy model. The moderator guide using open-ended key questions that allowed for participant's freedom of expression and added consistency and focus to the study (Stewart et al., 2007; Kruger, 1998a) was used for all interviews. The moderator guide had been translated into Spanish, and agreement of translation was reached with an experienced bilingual researcher. Furthermore, a committee of three bilingual women's healthcare master-prepared nurses concurred with moderator guide questions in both languages.

The questions focused on Pap smears, and a friendly and relaxed discussion ensued. Everyone had an opportunity to participate. The moderator kept the discussion on track, listened to participant's responses, and used both directive and nondirective interview styles (Stewart et al., 2007). In addition probes such as, *would you say that?* and short phrases such as *ok* or *Uh huh* were used to encourage further elaboration. The assistant moderator used probes such as "*I understand you said*…" for further elaboration, took notes, and summarized the discussion. At the end of the discussion, participants were given the opportunity to add anything not asked. The Newest Vital Sign [NVS] (Weiss et al., 2005) and demographic information were obtained following the discussion. Participants received a list of resources available in the community for free or

low cost Pap smears through The Breast and Cervical Cancer Services (BCCS) program and a $30.00 gift card.

Procedures: Individual Interviews

Individual interviews were also conducted in a private room at the senior centers. A smaller round table was used with two to three chairs with tape recorders in the middle of the table. An additional table was used for drinks. The researcher welcomed the participant, offered refreshments, and obtained informed consent. Participants chose a pseudonym from pre-written name cards. The researcher introduced the purpose of the study and followed the moderator guide. In addition to probes, short phrases such as *Uh huh* were used to signal attention and encourage participant to continue. Individual interviews concluded by asking the participant if she wanted to add anything more. The NVS and demographic information were obtained after the discussion. Participants were thanked for their participation. Each one was given a list of resources available in the community for free or low cost Pap smears through The Breast and Cervical Cancer Services (BCCS) program and a $30.00 gift card.

After all focus groups and individual interviews were completed, participants in both focus groups and individual interviews described similar experiences related to cervical cancer screening and health literacy. In addition, there was general consensus and negligent descent (Onwuegbuzie, Dickinson, Leech & Zoran, 2009) among participants within groups and between groups. Therefore, all data from focus groups and interviews were aggregated for analysis; there were 14 interviews in English and 16 in Spanish. Table 1 summarizes the interview procedures.

Table 1

Discussion Guide

Pre-discussion	Welcome and refreshments. • Greetings and introductions. • Written Script read out loud.
Discussion	Moderator guide (English/Spanish). Presented Brochures • *Cervical Cancer Awareness in Texas* (English/Spanish) • *Cervical Cancer: Inside knowledge, Get the facts about gynecological cancer* (English/Spanish)
Post-discussion	Presented the *Newest Vital Sign* 1. Followed by brief discussion. a. *What was easy?* b. *What was difficult*? 2. Demographic data obtained 3. Participants received $30.00 gift card 4. Participants received list of resources available in the community and printed material. 5. Questions answered.

Demographic Data

Descriptive statistics were used to analyze the demographic data. The statistics reflected a homogenous and compatible group. Group compatibility refers to personal characteristics such as needs and personality (Stewart et al., 2007). Participants were compatible; all attended a variety self-help groups offered through the senior centers; listened to each other's cervical cancer screening comments; and addressed each other in a friendly and polite discussion. Homogeneity refers to member characteristics, including age, gender, and socioeconomic status (Stewart, Shamdasani, & Rook, 2007). Given the nature and purpose of this study, all participants were female and their average age was 71. The majority (74%) were Mexican American by self-report and 79% were born in the United States. Sixty percent had a high school diploma or greater and 47% reported English as their primary language. The majority, 73%, reported Medicare as primary health insurance and median income of >$25,000.00/year. The majority, 70% of participants, reported that they were current (<3 years) with their routine Pap smear exam. Both group compatibility and group homogeneity are necessary for group cohesiveness or "what holds the group together" (Stewart et. al., 2007, p. 25), which makes the group more effective in reaching its goals (Stewart et al., 2007).

Hispanic ethnicity.

The term Hispanic is used to designate people whose ancestry or origins are from a Spanish-speaking country. It derives from the use of a language, Spanish (Cafferty & Engstrom, 2006), and the origin can be traced to Mexico or other Spanish-speaking countries (U. S. Census Bureau, 2010). The 2000 census added Hispanic/Latino as an

ethnic distinction (Bulatao & Anderson, 2004), and it is used interchangeably in the literature. Inclusion criteria to participate in the study included older women of Mexican American ancestry. The majority of participants (74%) self-identified as Mexican American, 17% self-identified as Mexican; therefore, the term Mexican American will be used whenever possible to denote the Hispanic/Latin subgroup of the participants by self-report. Table 2 summarizes focus group demographics (*n*=13) conducted in Spanish, while Table 3 summarizes focus group demographics (*n*=10) conducted in English. Table 4 summarizes group demographics (*n*=7) of individual interviews conducted in English and/or Spanish. Four participants were recruited for individual interviews in English and three participants were recruited for individual interviews in Spanish. Scheduled Spanish-speaking interviews were conducted as follows: one interview was in Spanish, one was in English, and one started in Spanish and ended in English. Table 5 summarizes total (*N*=30) group demographics.

Analysis

Both individual interviews and focus groups were conducted in English and/or Spanish, tape recorded and transcribed in the original language. Transcriptions were reviewed for accuracy in English or Spanish. Data were analyzed in the original language and later translated. Translation was not literal. Translation was for meaning since the meaning of words captures cultural characteristics (Shklarov, 2007), and grammatical errors can often be seen in literal translations (Zarcadoolas et. al., 2006). Other bilingual experienced qualitative researchers reviewed the translation of codes and themes and

Table 2

Summary of Focus Group Demographics Conducted in Spanish – $N = 13$

DEMOGRAPHIC		%
Average Age	73 years	
Place of Birth	U.S.	77
	Mexico	23
Marital Status	Married	54
	Widowed	39
	Divorced	7
Ethnicity	Mexican American	70
	Mexican	30
Primary Language	Spanish	46
	English	39
	English/Spanish	15
Education	<High school	54
	High School	23
	>High School	15
	Not reported	8
Income	Low	31
	Medium	38
	Not reported	31
Health Insurance	Medicare	70
	Private	23
	Not reported	7

Table 3

Summary of Focus Group Demographics Conducted in English – $N = 10$

DEMOGRAPHIC		%
Average Age	63 years	
Place of Birth	U.S.	70
	Mexico	10
	Other	20
Marital Status	Married	40
	Widowed	20
	Divorced	40
Ethnicity	Mexican American	90
	Other	10
Primary Language	Spanish	70
	English	10
	English/Spanish	20
Education	<High school	20
	High School	10
	>High School	70
Income	Low	50
	Medium	50
Health Insurance	Medicare	80
	Private	20

Table 4

Summary of Individual Interviews Conducted in English/Spanish – $N = 7$

DEMOGRAPHIC		%
Average Age	69 years	
Place of Birth	U.S.	72
	Mexico	28
Marital Status	Married	43
	Widowed	14
	Divorced	43
Ethnicity	Mexican American	57
	Mexican	14
	Other	29
Primary Language	Spanish	29
	English	29
	English/Spanish	42
Education	<High school	28
	High School	28
	>High School	43
Income	Medium	100
Health Insurance	Medicare	58
	Private	14
	None	14
	Missing	14

Table 5

Summary of Group Demographics ($N = 30$)

DEMOGRAPHIC		%
Average Age	71 years	
Place of Birth	U.S.	79
	Mexico	21
Marital Status	Married	47
	Widowed	26
	Divorced	27
Ethnicity	Mexican American	74
	Mexican	17
	American	3
	Other	3
	No answer	3
Primary Language	Spanish	30
	English	47
	English/Spanish	23
Education	<High school	37
	High School	20
	>High School	40
	Not reported	3
Income	Low	33
	Medium	23
	High	23
	Not reported	20
Health Insurance	Medicare	73
	Private	17
	None	3
	Not reported	7

reached agreement on translation. Similarly, observer notes were congruent with major themes identified.

Data were analyzed using qualitative content analysis, and five matrices (Bernard & Ryan, 2010) from interviews were developed using the major headings from Zarcadoolas et al.'s (2005) health literacy conceptual framework, which describes four domains: fundamental literacy, science literacy, cultural literacy, civic literacy, and media literacy with the moderator guide questions. The transcripts and matrices were color coded for ease of analysis. Figure 1 represents the color-coded scheme. For example, the heading Science Literacy is color coded green with the subheading, Knowledge of Pap Smears.

Each column was assigned a heading followed by data entry using text, direct quotes, and line numbers (Miles & Huberman, 1994). Table 6 represents a sample matrix and codes. A "case-by-variable matrix*"* (Bernard & Ryan, 2010, p. 290) was developed creating a coding scheme (Bernard & Ryan, 2010; see Appendix K). Once each matrix was developed, it was coded and analyzed individually (Miles & Huberman, 1994). After the data were collected, all matrices in each category of Zarcadolas et al.'s (2005) health literacy model were aggregated, coded, and analyzed, similar to a meta-matrix (Miles & Huberman, 1994). Themes from each domain of the theoretical model were elucidated. All data were found to fit into one of the themes. Intercoder agreement was achieved through frequent meetings and communication between researcher and experienced researchers/committee members.

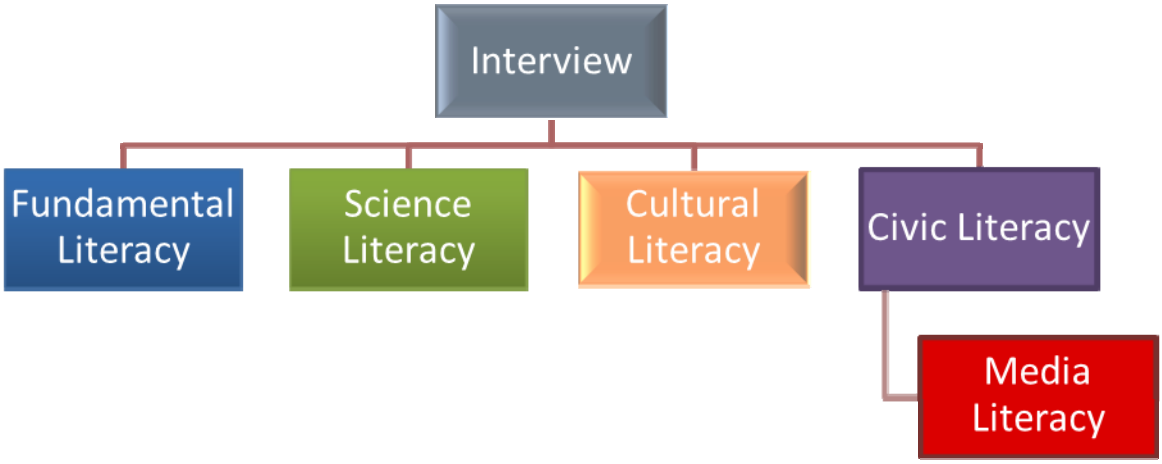


Figure 1. Color-coded matrices developed from interviews.

Table 6

Sample of Color-Coded Matrix and Codes from First Codes Matrix of English Focus Group: Science Literacy – Knowledge about Pap Smears

Impor-tant tests for women	**Helpful**	**Term Pap smear**	**Test for**	**Age to stop**	**What is diffi-cult?**	**Provi-der**	**Pre-vent**	**Cervi-cal cancer**	**HPV**	**Recommen-dations for younger**	**What makes it easy**
Pap smears 30	A woman afraid, scared, le da vergüen-za 35	Does not mean any-thing 67	To see if every-thing in you is all right 94	As long as alive 145	Older	Male/ female same 192	Stop smok-ing and drink-ing 237	Scared, fright-ening 281	I never have 293 Do not know	Young people do not want to listen to their mothers 333 Do not listen	To prevent from some-thing can come up 171

Findings

The data were coded and analyzed, and themes were elucidated from the matrices following Zarcadoolas et al.'s (2005) health literacy model to answer the research questions:(a) what are the beliefs and practices of English and/or Spanish speaking older women of Mexican American ancestry related to cervical cancer screening? and (b) what are the health literacy experiences of English and/or Spanish speaking older women of Mexican American ancestry related to cervical cancer screening? Each major theme was related to one of Zarcadoolas et al.'s (2005) main domains of health literacy: fundamental literacy, science literacy, cultural literacy, and civic literacy with its subheading of media literacy (Zarcadoolas et al., 2006). Matrices from each domain were aggregated and themes elucidated reflecting the overall health literacy experience related to cervical cancer screening.

Four major themes were revealed from qualitative data analysis to answer the research questions related to health literacy and cervical cancer screening practices and beliefs among older women of Mexican American ancestry. Each theme corresponds to one of the areas of health literacy: fundamental literacy, science literacy, cultural literacy, and civic literacy with its subcategory of media literacy as described by Zarcadoolas et al. (2005). The major themes are as follows: (a) *Reasons "I do not go"* (fundamental literacy), (b), *Prevention of cancer and "everything else"* (science literacy), (c) *We are different*, (cultural literacy), and (d) *There is always "consejos"* [advice, messages], (civic literacy) and from the subcategory of media literacy, (e) *Telenovelas* (soap-operas) teach a lot, and (f) *Learning from Internet brochures*. Table 7 shows the themes and

Table 7

Themes and Subthemes

1. **Reasons "I do not go" (Fundamental literacy)**
    a. " I don't feel bad, I don't need to go"
        i. Lack of symptoms
        ii. Fear
        iii. Never easy
    b. Speaking of language
        i. *Papanicolaou,* is it food?
        ii. I do not read in Spanish
2. **Prevention of cancer and "everything else" (Science literacy)**
    a. The doctor tells you when to have it.
    b. When to stop.
    c. That's news to me.
        i. What can we trust?
3. **We are different (Cultural literacy)**
    a. We did not talk about it.
        i. *Vergüenza* [shame].
    b. Female provider preferred.
    c. *Respeto* [Respect].
    d. Some men don't like it.
    e. Family first
4. **There is always "*consejos"* [advice, messages]. (Civic literacy)**
    a. *Telenovelas,* teach a lot. (Media Literacy)
    b. Learning from Internet brochures.
        i. Easy to read.
        ii. Don't leave us out.

subthemes within each area of health literacy, presented separately although they all intertwine, which supports Zarcadoolas et al. (2005) model.

Fundamental Literacy

Communication through spoken language plays a major role in how people receive health information (Zarcadoolas et al., 2006). Spoken language in addition to reading, writing, and interpreting numbers are essential skills of fundamental literacy (Zarcadoolas et al., 2005). The major theme for fundamental literacy is Reasons "I do not go." In addition, a literacy tool, The Newest Vital Sign (NVS) (Weiss et al., 2005) was given to participants (see Table 8 for score results). After administration of the literacy tool, a brief discussion regarding it ensued. The questions asked included *What did you like? What did you dislike? What was easy? What was difficult?*

The NVS consists of an ice cream label presented to the participant for review followed by six questions (Appendices F and G). Possible scores on the NVS range from 0-6, one point for each question, scores less than 4 indicate possible limited literacy whereas scores greater than 4 indicate possible adequate literacy (Weiss et al., 2005). The majority of participants scored <4, indicative of possible limited literacy. An independent *t*-test was used to compare NVS scores and interview language English/ Spanish using SPSS 19.0. There was no statistically significant difference ($p = 0.05$) between English-speaking (mean score = 2.36) and Spanish-speaking groups (mean score = 1.81); however, given the small sample size of 30 and a p value approaching significance, these findings must be interpreted with caution. It is clear from the mean scores that Spanish-speaking participants' health literacy was lower than English-speaking participants.

Table 8

Summary of Scores for Newest Vital Sign

Score	Percentage
Spanish (*N* = 16)	
0-1	50%
2-3	25%
4-6	25%
English (*N* = 14)	
0-1	43%
2-3	21%
4-6	36%

Score 0-1 = suggests high likelihood of limited literacy
Score 2-3 = indicates the possibility of limited literacy
Score 4-6 = almost always indicates adequate literacy

After administration of the NVS, a discussion of the literacy tool followed. All participants reported difficulty with the NVS, and not one said it was easy. When asked about the difficulties, one participant said, "It scares people ignorant about health and big words." In addition, participants could not relate to the ice cream label. Participants said that they do not eat ice cream and a different food label, one that is more familiar such as "pinto beans" would be easier for them to relate to. Furthermore, Spanish-speaking participants did not understand the word *helado* (ice cream) as written on the NVS. Instead the synonym *nieve* (ice cream) was the word understood by Spanish-speaking participants.

Reasons "I do not go."

Fundamental literacy was also addressed through focus group and individual interviews. The major theme elucidated is *Reasons "I do not go."* Most participants described their reasons for not attending cervical cancer screening: (a) lack of symptoms, (b) fear, and (c) never easy.

"I don't feel bad, I don't need to go." Participants described symptoms, which would prompt a medical visit that included pain, vaginal bleeding or vaginal discharge. One participant said, "I've heard from other women, they start with pain." Another participant said, "They are educated women. They just don't think they need to go because their body isn't telling them anything."

Lack of symptoms. Most participants associated lack of symptoms with overall health; therefore, a medical appointment was not needed. Participants comments

were the following: “We did not go unless we need to go” and “I do not feel bad, don’t feel sick, why do I need to go?”

Furthermore, some participants talked about stories from family and/or friends, in which, even in the presence of symptoms such as heavy vaginal bleeding, some women did not want recommended medical intervention such as a hysterectomy. One participant described such an encounter in which women [would say], *“Nací completa y me quiero morir completa*” [I was born whole and want to die whole].

Fear. Fear was also a deterrent to cervical cancer screening. Fear was associated with (a) pain or discomfort, and (b) test results. Participants reported that what they hear from other women makes them fear cervical cancer screening. Fear was related to the test itself because of discomfort and pain of the procedure. One participant said, “It is uncomfortable. Some people said it bothered them.” Other women were afraid of test results. One participant said, “They are afraid of knowing.”

Never easy. In addition to lack of symptoms and fear, participants unanimously stated that Pap smears exams were never easy: “It is *muy duro*” [very hard]. The difficulty of undergoing cervical cancer screening was associated with *vergüenza*, (embarrassment). Women acknowledged that the positive outcomes of cervical cancer screening outweighed the negatives. The most positive outcome described was a long healthy life. Negative outcomes included, discomfort, pain and fear. Many women said that even in the presence of fear, discomfort and lack of symptoms, Pap smear screening has to be done. One participant said, “*Tiene que hacérselo cada año y uno está más tranquila,*” [you have to do it once a year and then you are more at peace]. Another

participant said, “It is going to hurt, but it is going help me with my health.” Most women understood that fears had to be conquered to remain healthy and acknowledged that even though Pap smears were never easy, screening was important and necessary.

Furthermore, participants reported that women should seek routine cervical cancer screening because many women “*lo dejan a la desidia*” [leave it to chance]. All participants reported and advised other women to have a Pap smear before symptoms were present. One participant related her belief that women were “dying because they didn’t go” for screening. Another participant said, while “some women survive, some don’t.” Participants understood the importance of Pap smears on a regular basis before symptoms arose. One participant said, [do not wait to] “find out a friend had it and look what happened. It was too late.” Another participant said, “If you go before you start feeling bad, that helps you.”

Speaking of language. The meaning of words commonly used by health care providers about cervical cancer screening was not congruent with participants’ language. The following subthemes were revealed: *Papanicolaou, is it food?* and *don’t read Spanish*.

Papanicolaou, Is it food? Language and meaning are necessary for health communication and comprehension. In this study, words commonly used in cervical cancer screening were associated with (a) lack of meaning, (b) lack of understanding, and (c) code-switching.

Most Spanish-speaking participants did not understand the word commonly used in Spanish *Papanicolaou* (Pap smear). Most participants had never heard it before

researchers presented it in focus groups or individual interviews. One participant said, *"A veces cuando hablan así de Papanicolaou, a lo mejor es una comida"*[sometimes when they talk like that, Papanicolaou, maybe it is food]. Another participant said, "It sounds funny en *Español"* [It sounds funny in Spanish].

Similarly, English-speaking participants reported that the words *Pap smear* had no meaning in relationship to the procedure or test. Although women were familiar with the test, the words themselves had no meaning. When asked what Pap smears meant, participants responded by saying, "Does not mean anything," "The name does not focus me on the reason," and "*La palabra no te imaginas lo que es. No te reportan en la realidad*" [you don't imagine what the word is. It does not help you focus on the reality].

In addition to lack of understanding and lack of meaning of words associated with cervical cancer screening communication, participants would often change from one language to another. Code-switching, a common practice (Pfaff, 1979) among bilingual speakers (Auer, 1998) was heard throughout this study. English speaking participants would code-switch to Spanish when referring to reasons people avoided Pap smears, and the word *vergüenza* [embarrassed] was frequently code-switched. Similarly Spanish-speaking groups would code-switch to English to express technical terms including "uterine cancer," "breast cancer," and "radiation." This common phenomenon is important in health communication. It is the meaning of words (Zarcadoolas et al., 2006) that is essential to communication, education, and understanding of cervical cancer screening beliefs and practices. This central role of understanding and meaning has the potential to improve health outcomes since humans are meaning makers through the use

of language (Zarcadoolas et al., 2006, p. 74) and health information is communicated through language (Zarcadoolas et al., 2006).

I do not read in Spanish. Language is also communicated in print (Zarcadoolas et al., 2006). Print information in Spanish to Spanish-speaking participants was associated with (a) lack of reading ability and (b) lack of comprehension. The majority of Spanish-speaking participants could not read in Spanish although they could read in English. Therefore, in this study, written information was given in English per participant's request. In addition, participants reported that their formal education was in English and Spanish was only spoken at home. One participant said, "I grew up speaking both, but Spanish literature would take too long to read." A health literate individual needs to understand the meaning of written and spoken words as well as to understand scientific information (Zarcadoolas et al., 2006).

Science Literacy

Literacy in the sciences is described as "the level of competence with science, technology, and an awareness of the scientific process including" (a) knowledge of fundamental science, (b) understanding and comprehension of technology, and (c) understanding of scientific uncertainty and change (Zarcadoolas et al., 2005, p. 197; 2006). The major theme elucidated in the area of science literacy is *Prevention of cancer and "everything else"* (Table 7). Lack of knowledge, understanding, and emphasis on physician recommendation are a deterrent to cervical cancer screening.

Prevention of cancer and "everything else."

Initially participants in both focus group and individual interviews were asked to discuss what specific medical tests women should receive to stay healthy. Participants reported that screening tests and annual exams after age 50 were very important. One participant said, "annual exams, Pap smear, mammogram." Another participant said, "exámenes típicos de cada año" [typical yearly exams]. As part of the discussion, participants were asked questions related to scientific knowledge and understanding of cervical cancer screening, including *what do you think the test* [Pap smear] *is for?* Most participants said that Pap smears were for a variety of other reasons including prevention of diseases and cancer or vaginal discharge. One participant said, "*tratar de prevenir el cáncer y cualquier enfermedad si la agarran a tiempo*" [try to prevent cancer and whatever other disease if detected on time]. Another participant said, "to see if I have any kind of discharge or liquids." In addition, participants reported that Pap smears were for detection of other problems such as "cysts," "infections," and "everything else."

In addition to annual Pap smears and mammograms, the majority of women said that prevention of diabetes is a priority for Hispanics. Women said that diabetes screen, diet, weight control, and exercise were as important as other medical tests for Hispanics. Participant's comments regarding diabetes included "*esta enfermedad no es de pastillita*" [this disease is not just about a little pill]. Another participant said, "*lo que tenemos mucho los Mexicanos es diabetes*" [what we, Mexicans have a lot, is diabetes].

The doctor tells you when to have it. The major subthemes associated with cervical cancer screening were (a) *The doctor tells you when to have it,* and (b) *when to*

stop. These subthemes were associated with a deterrent and an incentive to uptake of cervical cancer screening. Physician recommendation was considered an incentive to cervical cancer screening since women adhered to medical advice. Lack of medical recommendation was a deterrent since most women do not seek cervical cancer screening. In regard to lack of recommendation, one participant said, "*los doctores no me preguntan, y no voy y les recuerdo"* [the doctors do not ask me, and I am not going to remind them]. Most participants relied on their health care provider for advice in regard to frequency of cervical cancer screening. All participants reported that the doctor decides whether screening tests are needed, depending on an individual's age, condition, and medical and family history. One participant said, "The doctor would know"; another participant said, "doctor said they did not need it." Participants relied on doctors' recommendations to continue or stop Pap smear screening and associated with a deterrent and an incentive to cervical cancer screening.

When to stop. Medical recommendation prompted participants to (a) start, or (b) stop cervical cancer screening. Most participants reported that there was no specific age to stop cervical cancer screening and said that Pap smears should continue "as long as we are women" and "as long as [we are] alive." Although, there was no age to stop, there were other reasons given to stop Pap smears including hysterectomy, menopause, and no longer sexually active. One participant said " *No pues, no tengo marido, no tengo sexo, no tengo hijos, yo no tengo regla, ya no necesito" "* [Well, I don't have a husband, I do not have sex, I do not have children, I no longer have a period, it is no longer necessary]. There were mixed responses to Pap smear screen after hysterectomy. Some women said it

was still needed; others were not sure; while others reported that Pap smears were no longer needed after hysterectomy. One participant said,*"no se necesita si ya te quitaron la matriz y los ovarios*" [it is no longer needed if they took out your uterus and ovaries].

Participants lacked knowledge of cervical cancer preventive measures such as limiting number of sexual partners, knowledge of HPV, and inadequate screening. Some participants acknowledged the fact that smoking causes cancer in general but did not know that it was a risk factor for cervical cancer. Limited knowledge of cervical cancer screening recommendations regarding cervical cancer screening was limited; they reported that a Pap smear was an all-encompassing test used for "prevention of cancer and everything else."

That's news to me. Human Papilloma Virus (HPV) and its relationship to cervical cancer were associated with new information. Frequent response to the question*, what do you think when you hear the term Human Papilloma Virus (HPV)?* was, "No, I do not know." Participants had not heard about HPV until presented by researchers. Some participants reported hearing through media about Governor Rick Perry's controversy to require young girls to receive the HPV vaccine. One participant said, *"era lo que el gobernador quería, inyectar a todas la niñas*" [it was what the governor wanted, inject all the young girls]. Although many participants reported hearing about the political controversy playing out in the media, they did not look into it any further and knew little else about it.

What can we trust? Women reported that in general it was hard to believe anything because health recommendations continue to change. There was a general lack

of understanding and trust of science from information reports presented in the media. Participants recalled recent news reports linking children's vaccines with autism. One participant said, "*mucha gente ya está contra las vacunas y los preservativos"* [many people are now against vaccines and preservatives]. Another participant said "I'm leery now about reports coming back on different procedures and tests." Most women felt confused and frustrated about the mixed health information presented through different media outlets. This sentiment is illustrated by a participant's comment: "One day hormones are good for you; another day they are not; or, one day vitamin E is good for you, another day it is not." There was a consensus of frustration and confusion related to changes in health recommendations and said that they do not know what to believe next.

Regarding science literacy, reliance on physician recommendation and lack of cervical cancer screening knowledge is associated with lack of action and empowerment. In addition to understanding science, culture and language play a central role in understanding health communication and education, which further supports a health literacy model that includes culture literacy.

Cultural Literacy

Cultural literacy is described as the individual's ability to (a) "recognize collective beliefs, world-view, and social identity in order to act on health information and the communicator's skill [and] (b) accommodate health information to cultural understandings of health information" (Zarcadoolas et al., 2005, p.197; 2006). Cultural literacy was intertwined throughout all interviews and all areas of health literacy. The major theme associated with cultural literacy is, *We are different*. All participants

recognized that Mexican American women were different from the main stream culture of the United States.

We are different.

Participants in focus group and individual interviews were asked questions in relation to group membership, such as, *What is the general attitude among friends and family regarding Pap smears?* Mexican American cultural norms and values were identified in all areas of health literacy. All participants reported that Mexican American culture and values were different from American mainstream culture. Hispanic core values include (a) *marianismo* (positive female characteristics), (b) *machismo* (Hispanic male characteristic), (c) *personalismo* (personal, friendly), *simpatía* (friendly, polite) *confianza* (mutual trust among individuals), (d) *respeto* (respect), and (e) *familismo* (the family). Hispanic core values were associated with both a deterrent and an incentive to cervical cancer screening.

The theme, *we are different,* was associated with being raised with different values and ideas. These values include *mariansmo* (positive female characteristics), the "ideal woman and mother," self-sacrificing and pure (Castellanos, 2000, p. 2). Participants reported these ideals and said that they were brought up differently with (a) strict rules, (b) old-fashion beliefs, (c) respect, (d) modesty, and (e) taboo subjects. One participant said, "It's not like it was when I was growing up."

The theme of being raised differently from an early age was illustrated by one participant's story. She recalled that "Hispanic girls are different" and stated that after swimming lessons, in the lockers, it was easy to know who the Latina girl was: "*usted*

pudiera ver la niña Latina, pues se baña con el traje de baño" [you would see the Latina girl, well, she is the one showering with her bathing suit]. Modesty was instilled in Hispanic girls from a very early age, which is associated with a deterrent to cervical cancer screening. In addition, certain subjects such as sexuality and cervical cancer screening were not talked about due to *vergüenza* (embarrassment). Subthemes within the theme of *we are different* include (a) *we did not talk about it*, (b) *female provider preferred*, (c) *Respeto,* (d) *some men don't like it,* and (e) *family first*.

We did not talk about it. This subtheme is associated with lack of information and communication between mothers to daughters. Lack of information reported among participants included such women's issues as menstruation, sexuality, and Pap smears. All participants reported that they did not receive any information from their mothers about women's health care issues, including menstruation or Pap smears, because it is considered a taboo subject and "never talked about." Some participants' commented: "our mothers had no voice" and "*a mi nunca me dijeron nada*" [they never told me anything]. Participants reported lack of information from their mothers related to cervical cancer screening and learned about it during their childbearing years.

Participants said that cervical cancer screening should be discussed among women, but it is not. One participant said, "Women don't discuss things like that amongst other women. Most really keep their things to themselves" and "do not go into details." Most women said that they are embarrassed to discuss personal matters such as Pap smears.

Vergüenza [embarrassment]. This subtheme was a deterrent to cervical cancer screening among older women of Mexican American ancestry. All participants reported that many Hispanic women do not attend cervical cancer screening because of *vergüenza* [embarrassment, shame]. This sentiment is expressed by anecdotes from other women as well as by the participants themselves. The experience of a pelvic exam was described as: "*vergüenza, ojos cerrados, tiesa*" [embarrassment, closed eyes, rigid]. A participant said, "A lot of women are embarrassed to go to the procedure especially Hispanic women"; yet another participant said, "*Típica Latina, somos mas vergonzosas*" [typical of other Latin women, we are very embarrassed]. This idea was expressed across all interviews. Despite feeling *vergüenza* (embarrassment), participants acknowledged the importance of overcoming embarrassment. Different ways in which women overcome *vergüenza* (embarrassment) towards Pap smears is to (a) make it a routine, (b) obtain accurate information, (c) realize the importance of the test, and (d) consult a female provider. One participant said that *vergüenza* (embarrassment) "can take you somewhere where you are going to be embarrassed and maybe even die."

Female provider preferred. A female healthcare provider helps to overcome the *vergüenza,* (embarrassment) experienced with cervical cancer screening. A female health care provider is associated with increased (a) comfort and (b) ease of exam, thereby decreasing *vergüenza* (embarrassment). Most women said it was easier to attend cervical cancer screening if the healthcare provider was a female and was associated with mutual gender understanding. Comments from focus group discussions and individual interviews

included “women are more comfortable with women” and “ a woman is more familiar with what we go through.”

The majority of participants said they preferred a female nurse practitioner. Women described the experience with female nurse practitioner as more relaxed and comfortable. One participant said, “I feel free to talk to the nurse.” Another participant said, “Nurse practitioners are more thorough, they check more things than a doctor.”

In addition to preferring a female healthcare provider, Hispanic values of *personalismo* (personal, friendly), *simpatía* (friendly, polite) and *confianza* (mutual trust among individuals), were expected in the healthcare encounter (Castellanos, 2000). One participant said it was important to have “a good relationship with your doctor, you feel better going for a Pap smear, because you are familiar.” The importance of establishing a personal rather than an institutional relationship with the health care provider was discussed throughout interviews (National Alliance for Hispanic Health, 2001).

Participants said it was important to establish a “good relationship” with the health care provider, which is associated with routine cervical cancer screening. One participant said, “*Yo tengo una relación con mi ginecólogo, ya es como familia*” (I have a good relationship with my gynecologist, he is like family.” This association included being a good listener. One participant said, “*Lo que a mi gusta es que el doctor hable contigo y te dice que va hacer”* [what I like is for the doctor to talk to you and tell you what he is going to do]. The Hispanic values of *personalismo* [personal, friendly], *simpatía* [friendly, polite] and *confianza* (trustworthy) were incentives to cervical cancer screening among older women of Mexican American ancestry.

Respeto *[Respect].* The Hispanic value of *respeto* was a common subtheme; every person needs to be treated with respect (National Alliance for Hispanic Health, 2001). Self-respect is associated with the value or *marianismo* (positive female role). One participant said, "When I was growing up, you could not bring anybody through the house, especially young men, have some respect." Women said that Hispanic girls have to be taught differently. Information, education, and *consejos* [advice] about cervical cancer screening had to be given with respect. Teachers and/or health care providers must be aware of the importance of *respeto* (respect) within the Mexican American community and present information accordingly. Information related to women's issues including sexuality and Pap smears should be presented in a firm, truthful, and respectable manner. One participant said, "Women have to be smart about their bodies." The value and importance of respect in the Mexican American community was seen unanimously across all interviews.

The value of *marianismo* [positive female characteristic] was also present in the discussion. Women are expected to fulfill the expected female role or *marianismo*. One participant said, "Women were expected to wait until marriage before initiating sexual activity where the men are *muy macho* [very manly or male Hispanic characteristic] with multiple sex partners," adding, *El hombre puede hacer y entre mas mujeres mejor, pues con mas mujeres se acueste mejor, porque es muy macho muy varonil. Y la mujer no, nada, que la fregada*!" [the male can do anything, the more women the better, the more women he sleeps with the better, he is very *macho* and manly. And the woman, no,

nothing, what a mess!]. Mexican American gender roles, lack of male support, and family values were associated with deterrents to cervical cancer screening.

Some men don't like it. Lack of male support and *machismo* (Hispanic male characteristic) were associated as deterrents to cervical cancer screening among Mexican American women. Participants reported that some Hispanic males are opposed to females seeing a gynecologist. One participant said, "*El marido dice, para que? Como te va a ver el médico*?" [the husband says, what for? How is it that the doctor is going to see you?]. Another participant said, "*Por machistas, y más el Mexicano*" [because they are *machistas*, and especially the Mexican male]. Women talked about how some Mexican men do not allow their wives to go for annual Pap smears. One participant said, "They just don't like it; some men are like that." Women said that although lack of male support was a deterrent to cervical cancer screening, women had to be their own health advocates. One participant said in reference to male objection to cervical cancer screening, "Q*ue te valga Chencha*" (common phrase used in Mexico, meaning, do not give it importance). In this case, the meaning of the phrase is that male opinion is to be disregarded and medical recommendations for Pap smears should be followed.

Family first. The Hispanic value of *familismo* [the family] was a common subtheme throughout all interviews. The theme of *familismo* was associated with a deterrent to cervical cancer screening among older women of Mexican American ancestry. *Familismo* is related to women's dedication to the family first, leaving little time for self-care, including Pap smears. The concept of family first is illustrated best by one participant,

> *Las Mexicanas están muy cerca de sus familiares y les importa mucho los familiares y se dejan ellas pasar, no piensan en uno mismo, allá en los hijos, las hijas, la familia primero* [Mexican women are very close to their families and their families are very important and they let themselves go, they do not think about themselves, they think about their sons and their daughters, the family first].

Mexican American women's priorities included caring for the family first. One participant said, "*El valor, la unidad familiar que existe en nuestra cultura es muy diferente*" [the value, the family unity that exists in our culture is very different].

Mexican American cultural ideas and beliefs were intertwined in all areas of health literacy (Zarcadoolas et al., 2005). Findings from interviews support the importance of cultural literacy as an integral component of health literacy. Mexican American cultural beliefs and values were associated with a deterrent and/or incentive to cervical cancer screening. These include *vergüenza* [embarrassment, shame], *respeto* [respect], *machismo* (male characteristics), *marianismo* [positive female characteristics], *familismo* [family first], and preference for female providers.

Civic Literacy

Civic literacy is defined as the "ability to help citizens become aware of public issues" and take part of the in the "decision-making process," including media literacy and Internet (Zarcadoolas et al., 2005, p. 197; 2006). The major theme elucidated in the area of civic literacy is *There is always 'consejos'* [advice, messages]. Subthemes that developed in the area of media literacy are *Telenovelas* [soap-operas] *teach a lot* and *Learning from brochures* (Table 7).

There is always *consejos* [advice, message]

Participants in focus group and individual interviews were asked questions related to public cervical cancer screening messages such as *where do you obtain information about Pap smears?* Participants reported receiving information about Pap smears from a variety of sources including the doctor's office, TV, women's magazines, *papelitos* [brochures], bilingual newspapers, and *Telenovelas* [Soap operas] (Table 9). Women received advice, *consejos,* from many diverse sources. However, participants reported that in many cases the information obtained was brief, and most would prefer to receive cervical cancer screening information from (a) *plaicas* (small group discussion), (b) a respectable source, and (c) annual reminders through U.S. mail.

Participants preferred *platicas* (small group discussions) in community centers for cervical cancer screening information. Furthermore, *platicas* present in-depth information, give women opportunity to interact with each, and evaluate the credibility of the source. One participant suggested providing information "through organizations of women that help women." A credible source of information would include someone who is a knowledgeable and respectable member of the community. One participant said, "I like to hear it from somebody that knows what they are talking about." Some examples of respectable members of the community given by participants were a doctor's office and some TV personalities, such as Vikki Carr. In addition, participants urged researchers to contact local media outlets, including bilingual newspapers (writing a column) about the importance of Pap smears, and continue to present information in community centers.

Table 9

Participant Use of Sources for Medical Information, $N = 30$

Source	# of Participants Selecting Source	% of Participants Using Source
MD office	23	77
TV	17	57
Magazines	11	37
Friends, family	7	23
Medical brochures	3	10
Internet	1	3
Nurses	0	0

Most participants said that more in-depth information should be disseminated through the media.

Media Literacy

Health messages are delivered to the public through the media. Media literacy, an area of civic literacy is described as the ability of individuals to understand judge and access health messages transmitted through television, radio, print, and the Internet (Zarcadoolas et al., 2006, p. 62). Media outlets preferred by most participants for receiving health information include television, magazines, and bilingual newspapers (Table 9). The Internet was not used as a source for obtaining health information. Subthemes identified in the area of media literacy were *Telenovelas* [soap operas] *teach a lot* and *Learning from brochures.*

Telenovelas [soap operas] teach a lot.

Media outlets including TV disseminate information through various formats. A popular entertainment format includes *Telenovelas*. Participants learn correct Spanish and *consejos* [advice] from *telenovelas*. Most participants were born and raised in the U.S. and formal education was in English. Spanish-speaking *telenovelas* present oral syntax, pronunciation, and vocabulary, bridging the gap from an all-English education. One participant said, *"Han puesto novelas para que agarren el idioma"*[they have presented soap-operas to learn the language]. Another participant said, *"Aprendemos correcto Español de las novelas"* [we learn correct Spanish from soap-operas].

In addition to learning Spanish, participants report that *telenovelas* (soap-operas) give a variety of *consejos* (advice) including health messages. One participant said, *"aprendemos de las novelas…era una telenovela de cáncer y mamogramas"* [We learn from the soap operas…there was a soap opera about cancer and mammograms]. Another participant said, "*Las novelas muchas de ellas dan mensaje. En medio de todo el desastre, ahí de que se odian y se aman, que nos divertimos mucho"* [many soap-operas give messages. In between all the disaster of love and hate, we have a lot of fun]." Women reported learning from other TV programs such as Dr. Oz that present health information. The majority of participants said that TV is a good tool for disseminating information; in contrast, the Internet was not used as a source of information.

Learning from Internet brochures.

The Internet, another media outlet, offers information to the public. Only one participant reported using the Internet to obtain information although not familiar with the websites from the CDC or from the Texas Department of State Health Services. Participants reported that they "did not trust it," "did not like," and "it was difficult to learn" to use the computer. The following are examples of participant's quotes: "I don't know about computers, I don't believe everything that goes on there" and "*me considero una persona 'smart', pero no tengo intención de aprender la computadora*" [I consider myself a smart person, but I have no intention to learn how to use the computer]. Another participant said, "Y*o no se ni prender la computadora*" [I don't even know how to turn on the computer]. None of the participants were aware of government websites available to the public through the Texas Department of State Health Services or the Centers for

Disease Control (CDC) or The Breast and Cervical Cancer Services (BCCS) program which offers free or low cost Pap smears. One participant said of the Internet, "it's not a tool to gain information."

Brochures related to cervical cancer screening available on government websites through the Internet were presented to participants. Participants were first presented with a brochure from the Texas Department of State Health Services (Appendix L) followed by a brochure from the Centers for Disease Control (CDC) (Appendix M). Both are available in English and Spanish.

Easy to read.

All participants preferred the simplicity and "eye catching" brochure from the Texas Department of State Health Services including the title, the colors, ease of reading, and the pictures. One participant said, "a picture says a lot, we go by pictures." In addition participants liked contact information provided, such as telephone numbers. None of the participants were aware of low cost services (BCCS) provided in Texas and were surprised to find out about HPV. After reading the brochure one participant said, "*Todavía nos cerramos los ojos ante la realidad. La detección temprana salva vidas, si pues sí"* [We still close our eyes to the reality. Early detection saves lives, yes, of course, yes].

In contrast, the majority of participants at first glance did not like the brochure from the CDC. They said it presented too much information all at once: "It is "too busy." The majority did not like the bright purple color. However, they said the information was very thorough and they liked the anatomical picture. In reference to the anatomical

picture, one participant questioned, “That is how I look inside?” Another participant said with surprise, “*Oh! Este es el cuello uterino*” [Oh! This is the cervix]. After reading the brochure, participants said that the information presented by the CDC might be more helpful after an oral presentation or *platica,* and then the brochure could be used for additional in-depth reading. However, women said that the information was important and helpful. One participant said, “We had nothing like this when I was growing up.”

Don’t leave us out.

The women said the brochures did not apply to women of their age. After reviewing the brochures, participants said that although ethnic Hispanic representation was noted in the brochure, there was a lack of age representation in the pictures shown on the brochures. Participants said that the brochures were geared more for younger women than rather than older women, and they said a picture of an older woman should be added. The following statements expressed this sentiment: “An older lady with gray hair”; “Don’t leave us out”; and, “We need another *viejita*” [little old lady]. Participants felt strongly about being represented on the brochure. Some said they would be willing to volunteer for the picture and said that a stronger representation of older women was needed. Participants described feeling left out and without age representation on the brochures.

In the area of civic literacy, participants did not know about cervical cancer screening services provided by local, state or federal government. TV is an important source of information and *telenovelas* deliver important messages. Participants did not use the Internet to access information. All participants preferred to receive information

that was easy to read with graphics and included a wider representation of older adults. All participants preferred to receive health information in small groups or *platica* rather than written information.

Summary

Overarching themes elucidated from focus group and individual interviews are (a) *Reasons "I do not go"*; (b) *Prevention of cancer and "everything else";* (c) *We are different;* and (d) *There is always consejos* (advice). Findings support Zarcadoolas et al.'s (2005) multidimensional model of health literacy.

The major theme of fundamental literacy is *Reasons "I do not go."* Older women of Mexican American ancestry described deterrents to cervical cancer screening associated with (a) lack of symptoms, such as vaginal bleeding or pain and (b) fear of the exam and of results, and (c) never easy. The majority of women (70%) were up-to-date with cervical cancer screening (<3 years). Women emphasized that although Pap smears were never easy, it was important and necessary. The negative outcomes of Pap smears such as discomfort and fear outweighed the positive outcomes of a long healthy life.

Fundamental literacy was partially assessed with a literacy tool, *The Newest Vital Sign* (NVS) (Weiss et al., 2005). The majority of women scored less than 4 on a scale of 0-6*, which* may be indicative of limited health literacy. Furthermore, women said they could not relate to the ice cream label presented in the NVS since it was not a common food for Mexican Americans.

Language is an integral part of fundamental literacy. Most women were familiar with the gynecological procedure, although the terms commonly used in cervical cancer screening such as Pap smear of *Papanicolaou* had no meaning.

The major theme of science literacy was *Prevention of cancer and "everything else."* Older women of Mexican American ancestry relied on physician recommendation for cervical cancer screening. A physician recommendation was both a deterrent and an incentive to cervical cancer screening. Women said if the doctor did not recommended the test, then it was not needed. Participants associated Pap smears with prevention of cancer plus "everything else" such as "infections" or "cysts." Limited knowledge of cervical cancer prevention measures included HPV and inadequate screening.

Cultural literacy predominated across all areas of health literacy; the overreaching theme was *We are different*. Hispanic core values such as *machismo* (Hispanic male characteristics), *marianismo* (positive female characteristic), and *familismo* (the family) were associated with a deterrent and an incentive to cervical cancer screening among older women of Mexican American ancestry. Women reported *machismo* (Hispanic male characteristic) as a deterrent to cervical cancer screening, and reported that male opinion in this case should be disregarded because women had to be their own health advocates. In addition, women reported that both males and females should receive information about cervical cancer screening.

The major theme of civic literacy was *There is always consejsos* (advice). Participants prefer to receive health information from (a) *platicas* (small group discussion), (b) respectable and knowledgeable source, and (c) reminders through U.S.

mail. Participants were not aware of low cost screening available through (BCCS). The Internet was not used and was not viewed as a tool to receive information. Media outlets preferred by participants included TV and bilingual newspapers. *Telenovelas* were viewed as a good medium to deliver health messages. Simple, easy-to-read text and graphics were preferable for print material. Participants preferred *platicas* or small group discussions as the primary source of health information. Findings from this study, discussion, and nursing implications will be discussed in Chapter Five.

Chapter Five

Summary, Implications, and Recommendations

This chapter presents the summary of the findings and discussion of the study as it relates to the literature. Implications of findings and future recommendations as they relate to health literacy and cervical cancer screening among older women of Mexican American ancestry are presented. The strengths and limitations of the study conclude this chapter.

Summary and Discussion of Findings

The purpose of this qualitative descriptive study was to explore the cervical cancer screening beliefs and practices and describe the health literacy knowledge and experiences of English and/or Spanish speaking older women of Mexican American ancestry as they relate to cervical cancer screening following Zarcadoolas et al.'s (2005) health literacy model encompassing four main domains: fundamental literacy, science literacy, cultural literacy and civic literacy (Zarcadoolas et al., 2005, 2006). Qualitative descriptive methods using focus group interviews are often used for exploratory research (Stewart et al., 2007) addressing Hispanic culture's oral traditions and social norms (Saint Germain et al., 1993). In addition, individual interviews in combination with focus groups are well suited to answer the research questions.

From a purposive convenience sample, 30 women agreed to participate in either focus group or individual interviews. A total of five focus groups and seven individual interviews were conducted in English and/or Spanish. After IRB approval, informed consent was obtained, and interviews lasting from 45 to 90 minutes in duration were

conducted from January through May 2012. Inclusion criteria to participate in the study included (a) Mexican and/or Mexican American women by self-report, (b) older than 50 years of age, (c) English and/or Spanish speaking, (d) living in the community without major visual, hearing, or mental impairments, and (e) without history of cancer. Descriptive statistics were used to analyze demographic data, summarized in Table 4. The majority (74%) of participants were Mexican American and 17% Mexican by self-report. Therefore, whenever possible, the following discussion will focus on Mexican American studies.

Interviews were transcribed and analyzed in the original language using qualitative content analysis. Codes were assigned in English or Spanish. Codes and themes in Spanish were translated after data analysis for meaning. In addition, bilingual researchers and committee members concurred with translations from Spanish to English. Five matrixes were developed (Bernard & Ryan, 2010) using headings from Zarcadoolas et al.'s (2005) health literacy conceptual framework; themes and subthemes were identified for each domain.

Themes and Subthemes

The four major themes elucidated from qualitative data analysis were (a) *Reasons "I do not go"*; (b) *Prevention of cancer and "everything else"*; (c) *We are different*; and (d) *There is always consejos* (advice, message). Each major theme correlates with one of Zarcadoolas et al.'s (2005) domains of health literacy (Table 7).

Reasons "I do not go": Fundamental literacy.

Participants reported that deterrents to cervical cancer screening included (a) lack of symptoms, (b) fear, and (c) never easy. In addition, women reported listening to stories from other women who do not attend cervical cancer screening because they do not have any symptoms.

"*I don't feel bad, I don't need to go*" in the present study was described by participants as a deterrent to cervical cancer screening. Most women reported that lack of symptoms, including pain, vaginal bleeding, or vaginal discharge, was associated with overall health; therefore, medical appointment was not warranted. Women acknowledged that it was preferable to attend cervical cancer screening before symptoms arose, but many women leave it to chance. These findings are consistent with current findings. Fernandez et al. (2009) conducted a feminist ethnographic study comprised of five focus groups of Spanish-speaking participants. The participants said that if they did not have any symptoms, they did not need a Pap smear. Similarly Wu et al. (2001) reported that older Mexican American women (75 years or older) were less likely to be screened than their younger counterparts (ages 67-74), and concluded that this difference may be related to fewer medical conditions. Furthermore, Hubbell et al. (1996) reported that Latina women who thought that screening was only necessary in the presence of symptoms were 70% less likely to be compliant with cervical cancer screening. The idea that medical appointments are only necessary in the presence of symptoms has been described in the literature as a barrier to preventive health utilization, including Pap

smears, among Mexican American/Latina women (Hubbell et al., 1996; Hunter et al., 2003; Otero-Sabogal, Stewart, Sabogal, Brown, & Pérez-Stable, 2003).

Fear was reported as a deterrent to cervical cancer screening. Participants said that many women are fearful of the procedure and/or results and said that many women do not want to know. Women reported that fear of discomfort and/or pain associated with Pap smears was also a deterrent to screening. These findings are consistent with, Fernández-Esquer et al. (2003), who reported that older women (>40 years old) were "less likely to want to know if they had cancer" (p. 484). In a survey with older Mexican American women Suarez, Nicholas et al. (1997) concluded that fear of cancer prevents Mexican American women from getting screened. Similarly, in a literature review Austin et al. (2002) reported that one of the barriers to cervical cancer screening among Hispanic women was fear of cancer. Fear or fatalism, or preferring not to know a cancer diagnosis, has been previously documented in Hispanic and cervical cancer screening literature (Arredondo et al., 2008; Behbakht et al., 2004; Chavez et al., 1997; Guilfoyle et al., 2007; Johnson et al., 2008; Powe & Finnie, 2003).

Women acknowledged that Pap smears were *never easy*, but very important and necessary. A study conducted to determine women's motivation to return to follow-up Pap smear using a scale of easy to difficult authors reported that 25% of Hispanic women would find it difficult to return for follow up and not easy. However authors did not further elaborate these findings (Breitkopf, Catero, Jaccard, & Berenson, 2004).

The majority (70%) of participants in the present study reported cervical cancer screening within three years. Reports are mixed. Authors of a cross-sectional study

conducted with Hispanic women older than 40 reported that 84% did not have a Pap smear (Hunter et al., 2003). In contrast, a study with older Mexican American women Randolph et al. (2002) reported that 64.1% of participants had a Pap smear within the last three years. Furthermore, authors concluded that self-reported data and cancer screening have been overestimated when compared to medical charts; although Hispanics had fewer screening tests compared to non-Hispanic white participants, there were not statistically significant differences (Hiatt et al., 1995).

Speaking of language. Participants reported that they were familiar with the gynecological procedure although the terminology commonly used in cervical cancer screening education had no meaning. This subtheme was further subdivided into two components (a) *I thought 'Papanicolaou' is it food?* and (b) *I do not read in Spanish.*

Papanicolaou, is it food? Spanish-speaking participants did not understand the word commonly used in Spanish *Papanicolaou* (Pap smear), although it is the same word in English but not commonly used by English speakers. Spanish words are not typically abbreviated, a common practice in the English language; therefore, the word Papanicolaou in Spanish does not change. In addition, participants in this study had not heard of the word before researchers presented the information during interviews, and participants in both English and Spanish-speaking interviews said that the word itself had no meaning. This researcher did not find any written articles related to the above findings. However, authors report that low literacy of some Latina women make words such as *risk* difficult to understand (Otero-Sabogal et al., 2003).

Researchers, however, have documented differences between English and Spanish speaking participants. Fernández and Morales (2007) concluded that after controlling for other factors such as health insurance, cancer-screening of women with differences between languages of interview disappeared. In contrast, studies have reported that English proficiency among Hispanic women has been associated with higher rates of Pap smear utilization than Spanish-speaking women (Arredondo et al., 2008; De Alba et al., 2004; Fernández & Morales, 2007; Hubbell et al., 2004; Jacobs et al., 2005). Roche et al. (1998) conducted a study of breast cancer with women ages 50 and older, finding that both English and Spanish-speaking women had poor understanding of breast cancer terminology commonly used in health messages. These authors concluded that Spanish-speaking older women had the lowest understanding of breast cancer technical terms. Furthermore, in a literature review, Davis et al. (2002) reported that "low health literacy is associated with limited health vocabulary" (p. 25) and understanding of concepts.

I do not read in Spanish was an unexpected and surprising finding. Many Spanish-speaking participants did not read in Spanish but could read in English. This author has not found any literature related to the above finding. The cross-cultural research literature includes the importance of translation of instruments and the inclusion of non-English speaking participants (Hazuda, 1996), but little information is available regarding language of interview, reading abilities, and place of formal education received (U.S. vs. Mexico).

The phenomenon of code-switching, changing from one langue to another (English/Spanish, Spanish/English) common in South Texas, was seen throughout all

interviews. This researcher did not find any literature addressing code-switching and cervical cancer screening or health messages. Participants code-switched from English/Spanish and Spanish/English. The word *vergüenza* [embarrassed] was frequently code-switched to Spanish in English-speaking interviews. Similarly, Spanish-speaking groups would code-switch to English when referring to technical terms such as "uterine cancer," breast cancer," and "radiation." Literature related to bilingual speakers shows that the ability of bilinguals to code-switch depends on the situation. Zentella (2006) reported that Puerto Rican children learn how to code-switch from English to Spanish or vice versa from an early age. For example, Spanish is more commonly used to address older women. Code-switching among bilinguals and the meaning of words is an essential component of fundamental literacy and understanding of health messages. This researcher did not find any literature addressing bilingual speech and cervical cancer screening messages and/or education materials.

Fundamental literacy was also partially assessed with a screening literacy tool *The Newest Vital Sign [NVS]* (Weiss et al., 2005). Possible scores range from 0-6. The majority of participants scored less than four, indicating the possibility of limited literacy. Of the Spanish-speaking participants, 75% scored less than 4 and 64% of English-speaking scored less than 4. Differences in NVS scores between Spanish-speaking and English-speaking participants were not statistically significant. The NVS has been used in primary care settings, and Heinrich (2012) found that two-thirds of participants in her study had a score of less than 3, which indicates the possibility of limited literacy similar to the present study findings. Furthermore, Heinrich reported that "none of the patients

expressed concern over the assessment" (p. 220). These findings differ from the current study; most participants said that they would not be willing to take the NVS at a doctor's office. Most participants in the present study could not relate to the ice cream label, because it was not frequently consumed. Participants suggested a different food label, one with which they could relate, such as "pinto beans." Furthermore, Spanish-speaking participants did not understand the word in Spanish for ice cream *helado,* but rather the synonym *nieve* was the term used. This researcher did not find any information in relation to the Spanish version of the NVS and translation issues. However, Andrulis and Brach (2007) wrote that translated instruments many times are not literally or cross-culturally validated. They recommend including native speakers when developing new instruments or materials.

Prevention of cancer and "everything else": Scientific literacy.

The major theme elucidated in the area of scientific literacy was *Prevention of cancer and "everything else."* Participants reported the importance of annual screening exams after age 50, and among the screening exams they mentioned as important for women were Pap smears. Participants said that Pap smears were for prevention of cancer and other gynecological problems such as "cysts," "infections," and "everything else." These findings are consistent with current research. Cooper, Polonec, and Gelb (2011) conducted a focus group study in the U.S. with women 40-60 years old. The researchers reported that most women believed that the Pap smear was used for multiple problems and that it was an "all inclusive" or "catch all" test (p. 521). Furthermore, Flores and Volker (2011) used case study methodology to investigate the decision-making process

used by older Mexican American women to attend cervical cancer screening. Authors reported that although the participants understood Pap smears to be for prevention of cervical cancer, it served other purposes as well such as "checking your back" (p. 6). Similar findings have been reported in other studies related to lack of knowledge and understanding of cervical cancer screening among Hispanic women (Arredondo et al., 2008; Bretikopf et al., 2005; Harmon et al., 1996; McMullin et al., 2005; Scarinci et al., 2003; Vanslyke et al., 2008).

Subthemes elucidated in the area of scientific literacy were (a) *the doctor tells you when to have it*, (b) *when to stop,* (c) *that's news to me,* and (d) *what can we trust?*

The doctor tells you when to have it. In the present study; participants described lack of physician recommendation as a deterrent to cervical cancer screening. Similarly, participants relied on physician recommendation to continue or stop cervical cancer screening. These findings are consistent with previous research. Harlan, Bernstein, and Kessler (1991) reported that among reasons given by women for not obtaining cervical cancer screening was lack of physician recommendation. Among Spanish-speaking women, 11% reported lack of physician recommendation as reason not to have a Pap smear. Similarly, Fernández-Esquer et al. (2003) conducted a study with Mexican American women living in Texas and reported that 52.5% of women believed that the "doctor should tell me if I need a Pap smear" (p. 483). Boyer et al. (2000) reported that barriers to cervical cancer screening among Hispanic women included lack of physician recommendation, while Austin et al. (2002) reported that physician recommendation is particularly significant for older women.

Participants in the present study also described the importance of a "good relationship" with the health care provider. They said it was important to have someone who is willing to listen as an incentive to seek cervical cancer screening. Hispanic cultural values described by participants were *personalismo* (personal, friendly), *simpatía* (friendly, polite), and *confianza* (trustworthiness) as incentives to cervical cancer screening. These findings are congruent with current findings of Otero-Sabogal et al. (2003), who reported that lack of trust in the medical establishment contributes to lack of screening in Latina women. Furthermore, the authors concluded that good physician communication, caring attitudes, and good listening skills improve screening among Latina women. In addition, Breitkopf et al. (2004) described that incentives to follow-up for abnormal Pap smear included a provider who displays good communication skills and takes time to talk to each person individually. On the other hand, physician or staff who are perceived to be rude were deterrents to follow-up.

When to stop. Most participants in the current study reported that there was no age recommendation to stop cervical cancer screening. These findings have been reported in the current literature. Cooper et al. (2011) in a focus group study reported that many women do not know how often Pap smears are recommended. In addition, Randolph et al. (2002) conducted a study in Southwest Texas with Mexican American women older than 50 years old, and found that older age women (65-74) vs. somewhat younger women (50-64) were less likely to have had a recent Pap smear, concluding that older patients may not be screened because physicians may not recommend screening after age 65.

Furthermore, Austin et al. (2002) reported that physician recommendation, in particular for minority women, was a "cue to action" (p. 125) to cancer screening.

That's news to me was a theme noted throughout all interviews. Participants had no knowledge of HPV and its relationship to cervical cancer and had not heard about HPV until presented by researchers. Some participants did report hearing about Governor Rick Perry's controversial mandate for HPV vaccine for young girls although most participants did not associate the political controversy with cervical cancer prevention. These findings are consistent with current research. Authors have reported women's misconceptions regarding Pap smears (Breitkopf et al., 2004). In a national study survey, Gelman, Nikolajski, Schwarz, and Borrego (2011) reported that Hispanic young women were less likely to know about HPV compared to white women. Similarly, a study with women ages 40 and older, Montgomery, Bloch, Bhattacharya, and Montgomery (2010) reported that 75% of women did not know the relationship between HPV and cervical cancer and concluded that older women had more inaccurate information. Furthermore, Fernández et al. (2009) in a focus group study conducted in the Texas-Mexico border region concluded that Hispanic men and women did not know the relationship between HPV and cervical cancer.

What can we trust? Participants reported frustration and confusion as health care recommendations keep changing. This finding is consistent with current cancer screening communication literature. Davis et al. (2002) reported that knowledge of cancer screening was often "confused" (p. 52). The Ramirez, Suarez, Laufman, Barroso, and Chalela (2000) study conducted with Hispanic women age 40 and older reported that

knowledge of Pap smear guidelines was a statistically significant predictor of recent Pap smear test. Mexican Americans were least likely to know Pap smear guidelines compared to other Hispanic subgroups. The authors concluded that regional characteristics of different Hispanic subgroups should be evaluated before implementing cancer-screening education.

We are different: Cultural literacy.

The predominant theme in the area of cultural literacy was *we are different*. Cultural literacy was intertwined in all dimensions of Zarcadoolas et al.'s (2005) multidimensional mode throughout all interviews, which further support the model. Older women of Mexican American ancestry recognized that they were different compared to the dominant American culture of the United States. Subthemes in the area of cultural literacy included (a) *we did not talk about it,* (b) *Female provider preferred*, (c) *Respeto*, (d) *some men don't like it,* and (e) *family first*. The theme *We are different* was associated with being raised differently with old -fashioned beliefs, respect, modesty, and taboo subjects such as sexuality.

We did not talk about it. All participants in the present study reported that there was a lack of communication and exchange of information between mothers and daughters regarding women's issues. Women's issues included menstruation, sexuality, and Pap smears. This lack of mother-daughter communication was related to *vergüenza* (embarrassment). Most women reported that they learned about cervical cancer screening in their childbearing years. Participants reported that communication about women's issues with their own [daughters and granddaughters] has improved, which may help

remove some communication barriers. This researcher did not find any literature specific to cervical cancer screening and mother-daughter relationships. However, these themes are closely related to traditional male-female roles, in particular the importance of modesty for older Mexican American women, which may be a barrier to cervical cancer screening (Galanti, 2003). In addition, authors have reported that Hispanic women considered sexuality a private matter (Hubbell et al., 1996). Although information regarding mother-daughter communication was not found, Boyer et al. (2000), who conducted a qualitative study with Hispanic women, reported that topics of sexuality among family were not discussed. Furthermore, lack of mother-daughter communication of sexuality and women's issues closely relates to modesty (Galanti, 2003) and privacy (Hubbell et al., 1996) reported by other authors.

Vergüenza (embarrassment). In the present study, participants reported that *vergüenza* (embarrassment) was a deterrent to cervical cancer screening. This finding is consistent with previous findings of Austin et al. (2002), who noted that barriers to cervical cancer screening among Hispanic women were related to embarrassment. Harlan et al. (1991) reported that one of the reasons given by women who do not attend cervical cancer screening was embarrassment.

Female provider preferred. Participants in this study said that a female healthcare provider helps to overcome *vergüenza* (embarrassment) and increases the comfort of a pelvic exam. This finding is consistent with current literature. Randolph et al. (2002) found a in a multivariate model that a female provider was a predictor of recent Pap smear test among older Mexican American women in southwest Texas. Similarly, Boyer

et al. (2000) reported that among Hispanic women lack of female Spanish-speaking provider was a barrier to cervical cancer screening. Furthermore, Alexander and McCullough (1981) concluded that female providers were essential to low-income Mexican American women and helped to reduce anxiety.

Respeto (respect). Women in the present study reported the importance of respect, including self-respect. The Hispanic value of respect was described unanimously across all interviews. Participants reported that women's issues including sexuality and Pap smears had to be presented with respect. Similarly, Otero-Sabogal et al. (2003) recommended that practitioners display respect among other cultural important attitudes during the health care encounter with Latina patients, which in turn will encourage cervical cancer screening.

Self-respect is related to *marianismo* (positive female role) and Hispanic gender roles. Traditional female roles are based on Catholicism, with an emphasis on being a wife and mother (Castellanos, 2000; Galanti, 2003). These beliefs are associated with modesty, (Galanti, 2003), virtue and high moral values (Chavez et al., 2001). Participants in the present study described Mexican American women's role expectations as a deterrent to cervical cancer screening, including the expectation of waiting until marriage to initiate sexual activity and the Hispanic male role of *machismo* the idea of virility and multiple sexual partners. Similarly authors conclude that immoral activity such as pre-marital sex along with modesty may impede Hispanic women from seeking cervical cancer screening (Chavez et al., 2001; Galanti; 2003).

Some men don't like it. Women in the present study reported that lack of male support or *machismo* (Hispanic male characteristic) was a deterrent to cervical cancer screening. Participants reported that Mexican men do not allow and do not like for their wives to attend cervical cancer screening. The present study does not include male's perspective but rather women's report of male expectation. Furthermore, participants reported that women should disregard male opinions in relation to cervical cancer screening, because women need to advocate for their own health.

These findings are congruent with previous research findings (Flores & Mata, 1995). In a study with Mexican and Mexican American males regarding attitudes toward wives' breast and cancer screening, responses were categorized into three levels: (a) lacked interest and scorn, (b) had a general understanding, and (c) had an interest in helping their wives. These researchers reported that older Mexican American males expected their partners to talk to other women about cervical cancer screening (Flores & Mata, 1995). In addition, Fernández et al. (2009) in a focus group study with both men and women of Mexican origin reported that males would suspect infidelity in the event of a positive HPV test and were aware of cultural beliefs of *machismso,* which impacted their first overall response. Authors concluded that after receiving information, *machismo* also had positive results: males wanted to take charge, get tested, be responsible, and expressed worry about their female counterpart's health.

Family first, or what has been termed in the literature as *familism,* a core value of Hispanic culture (Sabogal et al., 1987), was reported by participants in the present study as a deterrent to cervical cancer screening. This core value and emphasis of family first or

caring for family members first, leaves little time for self-care. Unlike other research reports, Suarez et al. (2000) reported that for older Mexican American women (>40 years old) social integration, close friends, and family had a positive relationship with Pap smear screen. Similarly, Boyer et al. (2000) reported that Hispanic women would wait to make health care decisions until the family has been consulted. Furthermore, Breitkopf et al. (2004) reported that Hispanic women described lack of family support as reasons some women would not follow-up on abnormal Pap test results.

There is always *consejos* (advice, messages): Civic literacy.

The major theme elucidated in the area of civic literacy was *there is always "consejos"* [advice, messages]. Participants in the present study reported receiving information from a variety of sources including doctor's offices, TV, women's magazines, bilingual newspapers and *telenovelas* [soap-operas]. Mass media and the Internet abound with health messages, which pose challenges for low health literacy women (Zarcadoolas et al., 2006). Women in the present study did not report Internet use for health information.

Themes elucidated under the subheading of media literacy were (a) *Telenovelas teach a lot* and (b) *Learning form Internet brochures*. Most participants in the present study prefer to receive information in small group discussion or *platicas* through credible sources including TV personalities and not the Internet. Participants reported that a credible source of information would be someone knowledgeable and respected in the community. Similarly, O'Malley, Kerner, and Johnson's (1999) reported that older participants mentioned the doctor more frequently than younger participants (52.1% vs.

33.3%) as the main resource of health education; and among all age and ethnic groups, 40% referred to the doctor as the main resource for health education. Participants reported other sources of health information, including television, magazines, and brochures (O'Malley et al.). In the area of communication research, Brodie, Kjellson, Hoff, and Parker (1999) reported that Latinos received health information from television and the doctor. The researchers also reported that Latinos expressed the need for expanded health programs and information regarding government-sponsored programs, concluding that mass media outlets play an important role in delivering health messages to the public.

Telenovelas teach a lot. Participants in the present study reported that they learned *consejos* (advice) and correct Spanish from *telenovelas*. Participants reported that the popular *telenovelas* (soap-operas) also communicate health messages, *consejos* (advice). Similarly, the communication literature reports that a *telenovela*, *Ladrón de Corazones,* introduced breast cancer education messages as part of the story line, which improved participant's knowledge of radiation and mastectomies (Wilkin et al., 2007). Likewise authors reported a 1-800-4- CANCER information number shown during the episode stimulated increased hot line calls. Thus, the authors concluded that health messages through television programming can increase knowledge, conversations, and hot line calls for Hispanics.

Learning from Internet brochure. Literacy skills are needed to navigate the Internet and understand and differentiate credible sources of information (Zarcadoolas et al., 2006). Participants in the present study reported that they did not use, did not trust,

did not like, and had no intention of using the Internet or computers for health information or any other type of information. Participants were not aware of government websites where health information about cervical cancer screening could be accessed. Furthermore, participants were not aware of government programs such as the Breast and Cervical Cancer Services (BCCS), which provide no, or low cost exams.

Findings from recent literature are mixed. In a study conducted by Hill, Burge, Haring, and Young (2012) in Texas, comprised of men and women of different ethnic backgrounds, the majority (52.3%) of whom were Hispanic, researchers reported that 48% of participants used the Internet for health information although the majority did not want to use the Internet for health information. Furthermore, the researchers reported that Spanish-speaking participants were the group least likely to use the Internet compared to other ethnic groups and concluded that use of the Internet for older, poor populations is lower that what has been reported. Zarcadoolas, Blanco, and Boyer (2002) reported in recent research conducted with low literate populations that some participants do not trust the information on the Internet while other participants are not sure whether to trust the information on the Internet. Participants in the present study did not trust the Internet. Zarcadoolas et al. (2002) conducted an ethnographic study of 24 participants of varying ethnicities and reported that most participants thought they would use the Internet and that it would be a helpful tool. The authors concluded that Hispanic participants would like to use the web to keep in touch with family and friends in their native countries. The Pew Report (2012) found that 53% of Americans older than 65 use the Internet, unlike the present study, in which participants did not use the Internet.

Easy to read. In the present study, participants were presented with two Internet brochures. All participants preferred the brochure from the Texas Department of State Health Services (2010) and said they preferred it because of the simplicity, ease of reading and the pictures. In contrast, participants did not like the brochure from the CDC (2010). They said it provided too much information; however, they liked the anatomical picture. In addition, participants suggested they would prefer a small group discussion or *platica* followed by additional in-depth reading from the CDC brochure. All participants preferred easy-to-read cervical cancer screening information with pictures and reported learning with pictures. Participants overwhelmingly preferred small group discussion or *platica* to receive cervical cancer screening information in which they could interact with each other and ask questions.

Meade et al. (2002) pilot tested the development of a Spanish-videotape to deliver breast and cervical cancer screening education. The researchers reported that 89% of women from Mexican origin liked the information presented in small classes which were open for questions and provided a comfortable atmosphere. Giordano et al. (2008) reported that the effectiveness of cervical cancer screening written materials may be overrepresented since women need a wide variety of skills to understand written information. The authors concluded that a multi-level approach, which includes different modes of communication, would be more effective.

Don't leave us out. Women in the present study reported that the brochures lacked age representation and that the brochures were geared toward younger women. Participants acknowledged that although ethnic representation was noted there was lack

of age representation. This researcher did not find any information in regard to age representation and brochures.

Implications of the Study

Cancer is now the leading cause of death for Hispanics (ACS, 2012, p. 2), with higher rates (64%) of cervical cancer incidence for Hispanics than for non-Hispanic whites, preventable through screening and vaccination (ACS, 2012). The U.S. Hispanic population rose 43% in 2010; those of Mexican descent, who represent the largest Hispanic group, rose by 54% in the last 10 years (Ennis, Rios-Vargas, & Albert, 2011). The present study adds to the cervical cancer screening research with older women of Mexican American ancestry and adds support for a multidimensional model of health literacy (Zarcadoolas et al., 2005). Findings from the present study are the basis for continued research.

Implications for nursing research.

Little is known about the meaning of commonly used terms in cervical cancer screening education and code-switching among older women of Mexican American ancestry. Further research to explore and describe the linguistic and cultural characteristics among older women of Mexican American ancestry is needed. Congruent with objectives to improve health literacy from the U.S. Department of Health and Human Services by providing linguistically and culturally competent health information in the community that uses evidenced-based health literacy practices and supports research aimed at improving health literacy, these future efforts would be the basis of meeting the nation's goals.

A surprising finding in the present study was that most Spanish-speaking participants did not read literature in Spanish but could read in English. If this finding is consistent among diverse groups, it would help inform researchers as well as health educators to assess language differences and understanding. Further research with women educated in the U.S. vs. women educated in Mexico is warranted. In addition, research that includes men and women is also needed.

Qualitative and quantitative studies are also needed to assess the application of the NVS among different Hispanic subgroups. Although Hispanic subgroups have Spanish language in common, some terms are more often or not at all used by different subgroups. As seen in the present study, the synonym of *helado* (ice cream) was not understood by participants and was translated out-loud by researchers to the word most often used in this geographic area, *nieve*. It is imperative that researchers take into account the area and population in which the research takes place. In addition, other food labels more representative of the community may be more acceptable. It should be noted that researchers in the present study encountered difficulties with the translation of the Newest Vital Sign (NVS) Spanish version. For example, omitted words made the questions difficult to understand, and researchers added words verbally to correct for the missing words. This researcher did not find any literature addressing the above issues and further investigation with diverse groups is warranted. Further research is also needed to cross-culturally validate the NVS; translating instruments from one language to another (English/Spanish) does not necessarily meet the cultural needs of a group.

Further clarification of linguistic terminology will help develop educational programs that are both culturally and linguistically appropriate. Educational interventions and programs incorporating communities' learning preferences and cultural and linguistic congruity aimed at increased cervical cancer screening have the potential to improve health outcomes for Hispanics in the U.S.

Further research is needed to include men, women with disabilities, women living in rural areas, and those women not receiving routine or recommended screenings.

Implications for healthcare policy.

According to the Texas Health and Human Services Commission (2012), the Texas Women's Health Program includes women 18-44 if they meet the family income and family size eligibility requirements. If eligible, women are entitled to one family planning exam per year, which might include a Pap smear. These age requirement leaves high-risk populations (>50) out of reach for cervical cancer screening. Although Texas has awareness campaigns through the Internet at www.cervicalcancertexas.com, none of the women in the present study were aware of these efforts. Neither were they aware of low cost services provided through the Texas Breast and Cervical Cancer Services (BCCS). Further efforts to develop community, state, and national health policy for reaching these populations are warranted.

National efforts through the 109th Congress of the United States of America enacted the "Gynecologic Cancer Education and Awareness Act of 2005" or "Johanna's Law," a national awareness campaign to increase knowledge and awareness of gynecological cancers, including distribution of public materials. These materials include

Cervical Cancer: Inside Knowledge, get the facts about gynecological knowledge through the CDC and Internet www.cdc.gov/cancer/knowlege. Women in the present study did not like the Internet brochure from the CDC. Women reported that it presented too much information and would be more useful for additional reading after a group discussion or *paltica*. However, participants liked the anatomical picture. Efforts to improve communication and understanding have been implemented through diverse government agencies, including the CDC.

The "Plain Writing Act of 2010" promotes communication that the public can understand; writing must be clear, concise, and well organized. However, simplification of language may not be enough to inform all audiences, and messages maybe lost. A comprehensive model which incorporates cultural, civic, science, and literacy components may be more beneficial (Zarcadoolas, 2010). Further efforts are needed to include all aspects of health literacy to promote culturally and linguistically appropriate understanding and communication.

Financial resources need to be redirected towards implementing grass roots programs within communities. All women in this study preferred small group discussion or *platica* to receive health information. These activities are congruent with Mexican American cultural values including *personalismo* (personal, friendly), *simpatía* (friendly, polite), *confianza* (mutual trust among individuals), and collectivism, none of which can be obtained through the Internet. One size does not fit all. The Internet does not reach the most vulnerable populations, and it is not the panacea that some would like it to be. Women in the present study did not use the Internet to obtain any information.

Implications for nursing practice.

Continued efforts to assess individual and community health literacy are imperative to nursing practice. A multilevel approach to health literacy further supports the premise of holistic nursing. Communication efforts through different mediums aimed at health promotion and disease prevention, including cervical cancer screening, will improve health outcomes for older women of Mexican American ancestry. The premise of holistic nursing also includes cultural competence. National Standards for Culturally and Linguistically appropriate Services (CLAS) in Health Care ensures that patients receive respectful care that is congruent with their culture and preferred language (Office of Minority Health, 2001). Nurses must be aware of current standards in order to provide safe, effective, and culturally competent Holistic care. Holistic nursing recognizes the whole-being, including cultural values and backgrounds. Cultural competence definitions abound, and nurses must possess an awareness and experience of others' perspectives of health and health care and include culture in all nursing roles (Barnes, Craig, & Chambers, 2000). Nurses play an important role in patient education. Best ways to improve education are community health programs and *platicas*, small group discussion.

Implications for nursing education.

A holistic nursing approach should be emphasized in all nursing curricula. This approach encompasses the whole being, including health beliefs and culture. Students should work toward discovering their own culture, increasing cultural knowledge, and becoming aware of the other's perspectives about health and illness. Furthermore, health literacy and communication should be integrated through the entire curriculum. This

study adds support for a multidimensional model of health literacy, which includes cultural literacy, communication differences, language, meaning, and interpretation of words. Literal translations of written or verbal communication are not enough; rather, students should learn to assess for the client's understanding of health recommendations. Furthermore, this study adds support to Mexican American cultural values of *respeto* (respect), *familism*o (family first), *marianismo* (Hispanic female characteristics), *machismo* (Hispanic male characteristics) that will assist nursing students to more effectively communicate with older women of Mexican American ancestry.

Limitations of the Study

The sample was a purposive convenience sample recruited from an urban area of South Texas. In general, the sample was better educated and had higher income than many older Hispanics, many of whom lack financial means and have low education attainment (Angel & Whitfield, 2007), and, as such, may not be representative of older women of Mexican American ancestry. Participants were recruited from a community center that provided self-help classes; therefore, the sample may have been more interested about a variety of health issues including screenings.

Limitations of the study include those limitations inherent in focus group qualitative research. Focus group research limits generalizations by the nature of obtaining a purposive convenience sample. The interaction within group members and interaction of researcher with the group members may preclude participants' responses (Stewart et al., 2007). In addition, some women may have agreed with other focus group members because they did not want to feel out of place with the group.

In bicultural research, the bilingual moderator/researcher above all has to recognize her identity and avoid crossing certain boundaries between researcher/ moderator and focus group (Barbour & Kitzinger, 2001). This challenge could be both strength and a limitation. The researcher was born, raised, and educated through high school in Mexico, and possesses the same cultural core values of the group. Furthermore, the researcher is in the full sense bicultural and bilingual since her parents come from two different ethnic backgrounds, Mexican and Anglo-American. The assistant moderator/ researcher, an experienced qualitative researcher, was bilingual and bicultural, born and raised in Colombia, and adheres to the same Hispanic core values. Some boundaries include access to minority women, which in some instances may not have access to other providers (Barbour & Kitzinger, 2001). Women in the present study were self-assured, self-directed, and attended self-help senior community centers. In addition, a majority of women reported medical coverage and up-to-date Pap smear screening. This may not be representative of older Mexican American women in the general populations. Most questions from the women to the researcher were related to the meaning of certain words, such as *Papanicolaou*. Researchers also provided further information and list of community services available for low cost or no cost Pap smear screening. In addition, limitation of the study include self-reported data, which has been found to be overestimated (Hiatt et al., 1995)

Strengths of the Study

The strengths of the study include those inherit in bicultural and focus group research. Focus group research methodology allowed the researcher to draw upon the

collective core values of the Hispanic culture and oral traditions of older women and is well suited to explore attitudes, beliefs, and understanding of cervical cancer screening practices. In addition, focus group research methods provide a platform to obtain rich data and ideas of the group, which may not be evident during individual interviews. Focus groups are used to explore many topics and with those not literate (Stewart et al., 2007). Individual interviews combined with focus group add richness and depth to the study (Morgan, 1996; Munhall, 2007).

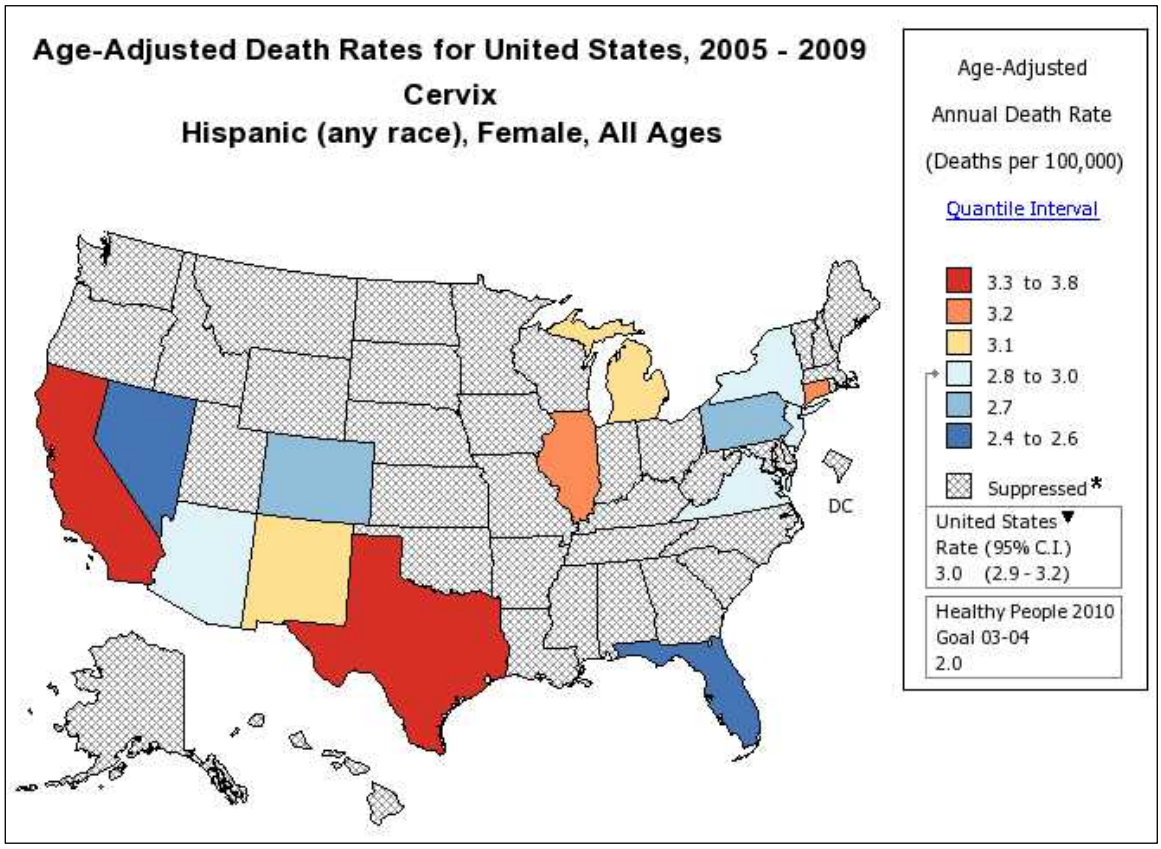
A bilingual, bicultural moderator/researcher born and raised in Mexico and assistant moderator/researcher born and raised in Colombia added strength to the study. The researchers did not need to employ interpretation of the data and were able to navigate the nuances of local and regional cultural and language norms. Language and core values of the researcher and participants were similar. This allowed participants to express themselves in English/Spanish or both languages with ease. In addition, in sharing common Hispanic expectations of *respeto* (respect), there was mutual understanding between researchers and participants of expectations from the encounter. Participants were allowed to meet and greet researchers and each other in the customary fashion and established rapport prior to start of the focus groups (Barbour & Kitzinger, 2001). Bilingual researchers validated data translation for meaning from Spanish to English. In addition, peer debriefing, journaling, and field notes added strength to the study.

Summary

The present study adds support for a multidimensional model of health literacy that includes cultural literacy (Zarcadoolas et al., 2005). There was a strong cultural component intertwined across all domains of health literacy. In the fundamental literacy domain, culture was intertwined through language, code-switching, and the meaning of words such as *Papanicolaou* and *fatalism*. Furthermore, Spanish-speaking participants could not read literature in Spanish but could read in English. Culture was intertwined in the area of civic literacy by participants' preference for small group discussion or *platicas* for cervical cancer screening information in congruence with collective values of Mexican Americans. In the area of medial literacy, culture took center stage as participants described *telenovelas* as venues to deliver *consejos* (advice, messages) and lack of trust in use of the Internet. In the area of science literacy, Mexican American cultural values for authority figures were expressed through reliance on physician recommendation for cervical cancer screening and the importance of respectable television personalities such as Vicky Carr. Cultural literacy Mexican American core values of *marianismo* (Hispanic female characteristic), *machismo* (Hispanic male characteristic), *familismo* (family first), *respeto* (respect), and *vergüenza* (embarrassment) were reported as deterrents to cervical cancer screening. Furthermore, the present study supports focus group and bicultural research aimed at understanding health disparities among older women of Mexican American ancestry that can lead to appropriate interventions.

APPENDIX A

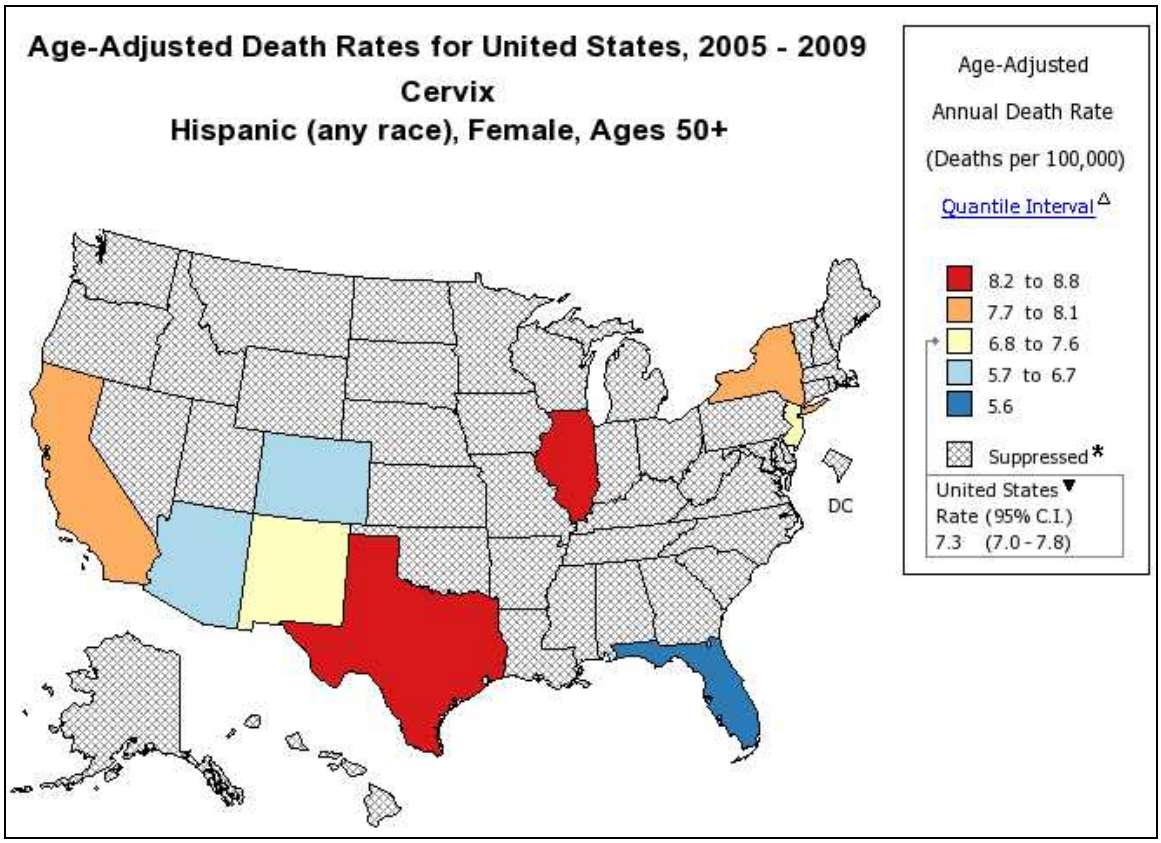
State Cancer Profiles 2005-2009, Cervix, Female, Hispanic, All Ages



From "National Cancer Institute State Cancer Profiles, Age-Adjusted Rates for United States, 2005-2009. Cervix. Hispanic (any race), Female, All Ages," National Center for Health Statistics. Retrieved from http://statecancerprofiles.cancer.gov/map/map.withimage.php?00&001&057&05&2&02&0&1&6&0#map

APPENDIX B

State Cancer Profiles 2005-2009, Cervix, Hispanic Female, Ages 50+



From "National Cancer Institute State Cancer Profiles, Age-Adjusted Rates for United States, 2005-2009. Cervix. Hispanic (any race), Female, Ages 50+," National Center for Health Statistics. Retrieved from http://statecancerprofiles.cancer.gov/map /map.withimage.php?00&136&057&05&2&02&0&1&6&0#map

APPENDIX C

University of Texas at Austin IRB Approval

OFFICE OF RESEARCH SUPPORT

THE UNIVERSITY OF TEXAS AT AUSTIN

P.O. Box 7426, Austin, Texas 78713 · Mail Code A3200
(512) 471-8871 · FAX (512) 471-8873

FWA # 00002030

Date: 12/22/11

PI: Bertha E. Flores

Dept: Nursing

Title: Health Literacy and Cervical Cancer Screening Among Older Mexican-American Women

Re: IRB Expedited Approval for Protocol Number 2011-09-0008

Dear Bertha E. Flores:

In accordance with the Federal Regulations the Institutional Review Board (IRB) reviewed the above referenced research study and found it met the requirements for approval under the Expedited category noted below for the following period of time: 12/19/2011 to 12/18/2012 . *Expires 12 a.m. [midnight] of this date.*

Expedited category of approval:

☐ 1) Clinical studies of drugs and medical devices only when condition (a) or (b) is met. (a) Research on drugs for which an investigational new drug application (21 CFR Part 312) is not required. (Note: Research on marketed drugs that significantly increases the risks or decreases the acceptability of the risks associated with the use of the product is not eligible for expedited review.)
(b) Research on medical devices for which (i) an investigational device exemption application (21 CFR Part 812) is not required; or (ii) the medical device is cleared/approved for marketing and the medical device is being used in accordance with its cleared/approved labeling.

☐ 2) Collection of blood samples by finger stick, heel stick, ear stick, or venipuncture as follows: (a) from healthy, non-pregnant adults who weigh at least 110 pounds. For these subjects, the amounts drawn may not exceed 550 ml in an 8 week period and collection may not occur more frequently than 2 times per week; or (b) from other adults and children, considering the age, weight, and health of the subjects, the collection procedure, the amount of blood to be collected, and the frequency with which it will be collected. For these subjects, the amount drawn may not exceed the lesser of 50 ml or 3 ml per kg in an 8 week period and collection may not occur more frequently than 2 times per week.

☐ 3) Prospective collection of biological specimens for research purposes by non-invasive means. Examples:
(a) Hair and nail clippings in a non-disfiguring manner.
(b) Deciduous teeth at time of exfoliation or if routine patient care indicates a need for extraction.
(c) Permanent teeth if routine patient care indicates a need for extraction.
(d) Excreta and external secretions (including sweat).

(e) Uncannulated saliva collected either in an un-stimulated fashion or stimulated by chewing gumbase or wax or by applying a dilute citric solution to the tongue.
(f) Placenta removed at delivery.
(g) Amniotic fluid obtained at the time of rupture of the membrane prior to or during labor.
(h) Supra- and subgingival dental plaque and calculus, provided the collection procedure is not more invasive than routine prophylactic scaling of the teeth and the process is accomplished in accordance with accepted prophylactic techniques.
(i) Mucosal and skin cells collected by buccal scraping or swab, skin swab, or mouth washings.
(j) Sputum collected after saline mist nebulization.

☐ 4) Collection of data through non-invasive procedures (not involving general anesthesia or sedation) routinely employed in clinical practice, excluding procedures involving x-rays or microwaves. Where medical devices are employed, they must be cleared/approved for marketing. (Studies intended to evaluate the safety and effectiveness of the medical device are not generally eligible for expedited review, including studies of cleared medical devices for new indications).
Examples:
(a) Physical sensors that are applied either to the surface of the body or at a distance and do not involve input of significant amounts of energy into the subject or an invasion of the subject's privacy.
(b) Weighing or testing sensory acuity.
(c) Magnetic resonance imaging.
(d) Electrocardiography, electroencephalography, thermography, detection of naturally occurring radioactivity, electroretinography, ultrasound, diagnostic infrared imaging, doppler blood flow, and echocardiography.
(e) Moderate exercise, muscular strength testing, body composition assessment, and flexibility testing where appropriate given the age, weight, and health of the individual.

☐ 5) Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for non-research purposes (such as medical treatment or diagnosis).
Note: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. 45 CFR 46.101(b)(4). This listing refers only to research that is not exempt.

☒ 6) Collection of data from voice, video, digital, or image recordings made for research purposes.

☒ 7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.
Note: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. 45 CFR 46.101(b)(2) and (b)(3). This listing refers only to research that is not exempt.

☐ Use the attached approved informed consent document(s).

☒ You have been granted a Waiver of Documentation of Consent according to 45 CFR 46.117 and/or 21 CFR 56.109(c)(1).

☐ You have been granted a Waiver of Informed Consent according to 45 CFR 46.116(d).

Responsibilities of the Principal Investigator:

1. Report immediately to the IRB any unanticipated problems.

2. Submit for review and approval by the IRB all modifications to the protocol or consent form(s). Ensure the proposed changes in the approved research are not applied without prior IRB review and approval, except when necessary to eliminate apparent immediate hazards to the subject. Changes in approved research implemented without IRB review and approval initiated to eliminate apparent immediate hazards to the subject must be promptly reported to the IRB, and will be reviewed under the unanticipated problems policy to determine whether the change was consistent with ensuring the subjects continued welfare.

3. Report any significant findings that become known in the course of the research that might affect the willingness of subjects to continue to participate.

4. Ensure that only persons formally approved by the IRB enroll subjects.

5. Use only a currently approved consent form, if applicable.
   Note: Approval periods are for 12 months or less.

6. Protect the confidentiality of all persons and personally identifiable data, and train your staff and collaborators on policies and procedures for ensuring the privacy and confidentiality of subjects and their information.

7. Submit a Continuing Review Application for continuing review by the IRB. Federal regulations require IRB review of on-going projects no less than once a year a reminder letter will be sent to you two months before your expiration date. If a reminder is not received from Office of Research Support (ORS) about your upcoming continuing review, it is still the primary responsibility of the Principal Investigator not to conduct research activities on or after the expiration date. The Continuing Review Application must be submitted, reviewed and approved, before the expiration date.

8. Upon completion of the research study, a Closure Report must be submitted to the ORS.

9. Include the IRB study number on all future correspondence relating to this protocol.

If you have any questions contact the ORS by phone at (512) 471-8871 or via e-mail at orsc@uts.cc.utexas.edu.

Sincerely,

James Wilson, Ph.D.
Institutional Review Board Chair

APPENDIX D

Demographic Information

Pseudonym_____

Today's date_____

1. Age_____

2. Marital Status
   Single (never married)
   Married
   Separated
   Divorced
   Widowed

3. Place of birth_____

4. Primary Language
   English
   Spanish

5. Ethnicity
   Mexican
   Mexican American
   Mexican origin
   Other_____

6. Education
   Less than elementary school
   Elementary School
   Less than high school
   High school
   Technical/vocational School
   Some college
   College graduate

7. Approximate date of your last pap smear
   One year ago
   Two years ago
   Three years ago
   Four years ago
   Five years ago
   More than five years
   Never
   Other_____

8. Annual Household income
   Less than $20,000
   $20,000-$29,000
   $30,000-$39,000
   $40,000-$49,000
   $50,000-$59,000
   $60,000 or more

9. Health insurance
   Medicaid
   Medicare
   Carelink
   Private
   Do not have insurance

10. Where do you most often obtain medical information?
    Doctor's office
    Nurse
    Radio
    Television
    Magazines
    Medical brochures
    Family
    Friends

11. Zip code_____

APPENDIX E

Moderator Guide, English

Introduction (5 Minutes)
Good Morning, my name is Penny Flores, and I will lead this group today. Welcome to our focus group discussion.

I would like to go over some guidelines for our present discussion. We want everyone to be comfortable talking and bringing up their ideas and thoughts. There are no right or wrong answers. Everything you say is important- so please lets all talk. Do not be afraid to say what you think even if you disagree or it sound different from someone else. We expect people to have different ideas.

We will all agree to be respectful of each other's comments and avoid interrupting each other. We want to hear everyone's comments. I will make sure to look around for people who have something to say.

We have much to talk about in the next hour or so. If I am moving too fast please be sure to stop me at anytime. My goal is to let everyone share their thoughts and opinions. Are we all in agreement?

We will agree to keep our conversations in confidence and we will not share with anyone outside this room. Even though the conversation is being taped, nothing you say will be connected with your name. Everything will be anonymous. Everyone agree?

Please if you feel you need to leave for any reason do not hesitate.

Science Literacy, Knowledge about Pap Smears and cervical cancer screening.

We are here today to talk about pap smears and health information to help us develop new materials about Pap smears and other women's tests (20 minutes)

1. What tests do you think women need to get to protect their health?

2. What do you think of when you hear the term pap smear?

    a. How many of you are familiar with this test?
    b. What do you think the test is for?
    c. How is the test done?
    d. Is there an age where the test should be stopped? What age?
    e. Are there other reasons to stop the test?

3. How often do you think someone should have a pap smear?

    a. When should someone go for a Pap smear?
    b. What makes it easy for someone to go for a Pap smear?
    c. What makes it hard for someone to go for a Pap smear?

4. What do you think prevents cervical cancer?

    a. Are there things people can do to prevent cervical cancer?
    b. What would be most important?

5. What do you think of when you hear the term cervical cancer?

6. What do you think of when you hear the term Human Pappilloma Virus?

    a. Have you heard about a vaccine?
    b. At what age should the vaccine be administered?
    c. Would you recommend it to a younger person?

Civic Literacy and Pap smears (15 minutes)

We would like to know where you receive health information in particular about Pap smears.

1. Where do you obtain information about Pap smears?

2. Who do you prefer to receive health information from?

3. How would you like to receive this information?

4. What do you like or dislike about the information you have received

Media Literacy and Pap smears (15 minutes)

Now I would also like to know what you think about the brochures and information presented on this table.

1. What do you like about the information presented?

2. What do you do not like?

3. What would you change?

4. Do you think the information would help you obtain a Pap smear?

    a. What was most helpful?
    b. What was least helpful?

Cultural literacy (20 minutes)

When you receive health information about Pap smears do you think the information was designed with someone like you in mind? For example; someone that shares similar culture and values as you.

1. What is the general attitude among your friends and family regarding Pap smears?

2. Is there anything in your culture that affects your views? Tell me about that.

3. Are there any religious or cultural pressures, which make it hard to obtain a Pap smear?

4. Did your mother talked to you about Pap smears?

5. Would you talk to your younger family members (daughters or granddaughters) about Pap smears?

    a. Would it be easy to talk about it?
    b. Would it be difficult to talk about it?

6. What would you advice women about Pap smears?

Fundamental Literacy[1]

We know many people read health information brochures at the doctor's office but in many cases they are difficult to understand. I am trying to understand what is the best way to provide the information.

1. *The Newest Vital Sign* (Weiss et al., 2005), a screening literacy test available in English and Spanish (5 minutes)

    It includes one scenario, an ice cream label and 6 questions

[1] NVS Copyright Pfizer Inc. Reproduced with permission.

Questions:

1. If you eat the entire container, how many calories will you eat?

2. If you are allowed to eat 60g of carbohydrates as a snack, how much ice cream could you have?

3. Your doctor advices you to reduce the amount of saturated fat in you diet. You usually have 42 g of saturated fat each, which includes one serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day?

4. If you usually eat 2500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one more serving?

Pretend you are allergic to the following substances: Penicillin, peanuts, latex gloves, and bee stings.

5. Is it safe for you to eat this ice cream?

6. If the answer if no, ask, why not?

(Weiss et al., 2005)

APPENDIX F

Moderator Guide, Spanish
Guía del asesor/asesora

Introducción (5 minutos)
Buenos días y bienvenidos, me llamo Penny Flores y voy a conducir este grupo de enfoque.

Aquí con nosotros también se encuentra la Dra. Lyda Arevalo quien va a tomar notas.

Primeramente me gustaría platicar acerca de las guías para la platica de hoy. Queremos que todos se sientan a gusto en discutir o presentar sus ideas y opiniones. No existen respuestas correctas o incorrectas. Simplemente queremos que todos participen porque sus opiniones son muy importantes para nosotros. No tengan temor de expresar su opinión aunque sea diferente a la de otra persona o personas. Esperamos que existan opiniones diferentes.

Tenemos que estar de acuerdo en que hay que tener mutuo respeto de las opiniones de otras personas. Al igual tenemos que estar de acuerdo en no interrumpir los comentarios de otra persona. Así tendremos la oportunidad de oír los comentarios de todos. Estaré pendiente de darle la oportunidad de hablar a todo el que tenga algo que decir.

Tenemos mucho que platicar en la próxima hora, hora y media. Si vamos demasiado rápido, por favor déjemelo saber. Lo principal es que todos tengan la oportunidad de expresar su opinión. ¿Estamos de acuerdo?

Algo muy importante en la cual todos tenemos que estar de acuerdo es que la discusión que se llevara acabo es completamente privada y confidencial. Por lo cual debemos de estar de acuerdo en que no se va a discutir fuera de esta sala de conferencia. Aunque la conversación va a ser grabada nada de lo que usted dice va a ser relacionado con su nombre verdadero. Todo será anónimo. Estamos todos de acuerdo? Perfecto.

Si alguien siente la necesidad de retirarse o salirse por cualquier razón, por favor no duden en hacerlo.

Conocimiento científico/ conocimiento acerca del Papanicolaou y prevención del cáncer cervicouterino.
Estamos aquí ahora para hablar acerca del papanicolau y la información de salud que recibe para tratar de producir mejores materiales con información acerca del tema y otros examines para mujeres. (20 minutos). En su opinión.

1. ¿Cuáles cree que son los exámenes que necesitan las mujeres para proteger su salud?

   a. Dígame que tan importante creen ustedes que estos exámenes son para las mujeres.

   b. ¿Puede pensar en razones por las cuales unas mujeres no se hacen estos exámenes?

2. ¿En qué piensan cuando oye la palabra Papanicolaou?
   a. ¿Cuántas personas han oído de este examen?
   b. ¿Para qué creen ustedes que se hace este examen?
   c. ¿Cómo se hace este examen?
   d. ¿Hay alguna edad en la cual ya no es necesario hacerse el examen? ¿Qué edad?
   e. ¿Hay alguna otra razón o razones en la cuales ya no se necesita el examen de Papanicolaou?

3. ¿Qué tan seguido piensan que una persona necesita hacerse un examen de Papanicolaou?
   a. ¿Cuándo hay que hacerse un examen de Papanicolaou?
   b. ¿Qué cosas facilitan que una persona se haga un examen de Papanicolaou?
   c. ¿Qué cosas dificultan que una persona se haga el examen de Papanicolaou?

4. ¿Qué creen ustedes que previene el cáncer del cuello de la matriz? (cervicouterino)
   a. ¿Creen ustedes que hay ciertas cosas que la gente puede hacer para prevenir el cáncer cervicouterino?
   b. ¿Cuál sería la más importante?

5. ¿En qué piensan cuando oyen el termino cáncer cervicouterino o cáncer del cuello de la matriz?

6. ¿En qué piensan cuando oyen el termino Virus de Papiloma Humano?
   a. ¿Han oído acerca de la vacuna?
   b. ¿A qué edad se recomienda la vacuna?
   c. ¿Ustedes recomendarían la vacuna a personas jóvenes?

Conocimiento Cívico y examen de Papanicolaou (15 minutos)

Ahora nos gustaría saber acerca de donde reciben información específicamente del examen de Papanicolau.

1. ¿Donde reciben información acerca del Papanicolaou?

2. ¿De quién prefieren recibir información acerca de salud?

3. ¿Cómo prefieren recibir esta información?

4. ¿Qué cosas les gustan o no les gustan de la información que han recibido?

Conocimiento de los medios de comunicación y el Papanicolaou (15 minutos)
Ahora nos gustaría saber que es lo que piensa acerca de los folletos de información que tenemos aquí.

1. ¿Qué les parece la información presentada en los folletos?

2. ¿Qué cosas no les gustan?

3. ¿Qué cambiaria?

4. Ustedes creen que esta información les ayudaría a obtener su Papanicolaou?
   a. ¿Qué fue lo más útil?
   b. ¿Qué fue lo menos útil?

Conocimiento Cultural y el Papanicolaou. (20 minutos)
Cuando ustedes reciben información acerca del Papanicolaou, ustedes ¿piensan o creen que esta información fue diseñada teniendo en mente a alguien como usted? Por ejemplo; con alguien con los mismos valores culturales de ustedes?

1. ¿Cuál es la actitud general de sus amigas o familiares acerca del Papanicolaou?

2. ¿Existe algo en su cultura que afecta su opinión? ¿Me pueden decir algo acerca de eso?

3. ¿Existen presiones culturales o religiosas por las cuales se les dificulta obtener un Papanicolaou?

4. ¿Sus madres les platicaron acerca de los Papanicolaou?

5. ¿Ustedes platicarían o han platicado con personas mas jóvenes en su familia. (hijas o nietas) acerca del Papanicolaou?
   a. ¿Sería fácil platicar de este examen?
   b. ¿Se les haría difícil platicar acerca de esto?

6. ¿Qué recomendaciones darían ustedes a las mujeres acerca del Papanicolaou?

Conocimiento Fundamental[2]

Sabemos que mucha gente lee información presentada en folletos pero en muchos casos es muy difícil entender esta información. Estoy tratando de entender la mejor manera de presentar esta información.

Un examen de investigación existe en Ingles y en Español The Newest Vital Sign (Weiss et al., 2005). (5 minutos)

Incluye una representación de una etiqueta impresa en una pinta de helado (nieve). Y seis preguntas que son leídas en voz alta.

Preguntas:

1. Si usted se come todo el helado en el envase, ¿Cuántas calorías habrá consumido?

2. Si a usted le recomendaron consumir 60 gramos de carbohidratos en la merienda. ¿Cuanto helado puede comer?

3. Su medico le aconseja reducir la cantidad de grasas saturadas en su dieta. Usted normalmente consume 42 gramos de grasa saturada al día, que incluyen una porción de helado. Si deja de comer helado, ¿cuántos gramos de grasa saturada consumiría al día?

4. Si usted normalmente come 2500 calorías al día, ¿Qué porcentaje de su valor diario de calorías habrá consumido si se come una porción?

Imagínese que usted es alérgico a las siguientes sustancias: Penicilina, cacahuates , guantes de caucho (latex) y picaduras de abeja

5. ¿Puede comer este helado con seguridad?

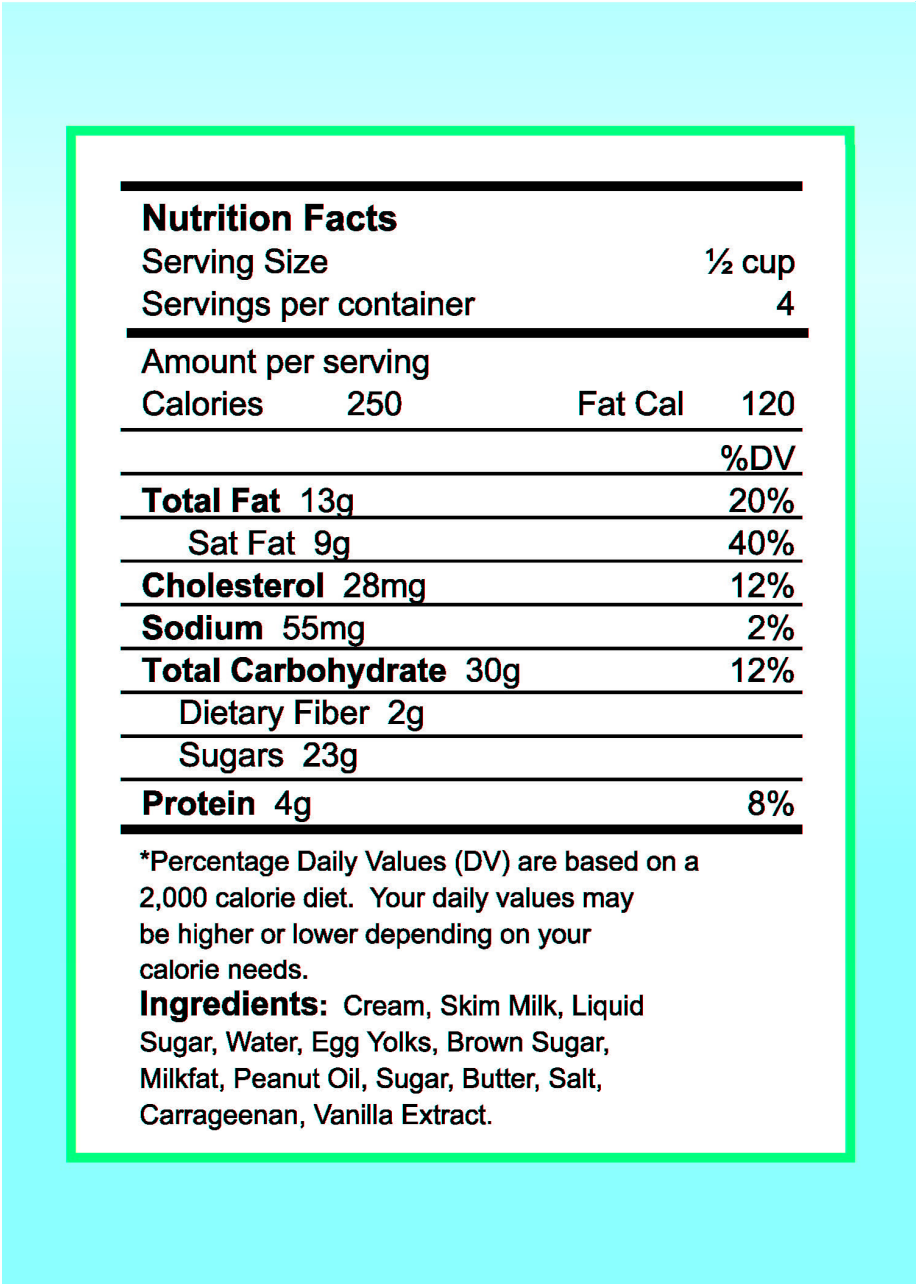
6. Si la respuesta fue "no", ¿Por qué no?

(Weiss et al., 2005, p. 517)

[2] NVS Copyright Pfizer Inc. Reproduced with permission.

APPENDIX G

Weiss et al. (2005) Screening Literacy Tool - English



Nutrition Facts

Serving Size	½ cup
Servings per container	4
Amount per serving	
Calories 250	Fat Cal 120
	%DV
Total Fat 13g	20%
Sat Fat 9g	40%
Cholesterol 28mg	12%
Sodium 55mg	2%
Total Carbohydrate 30g	12%
Dietary Fiber 2g	
Sugars 23g	
Protein 4g	8%

*Percentage Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.

Ingredients: Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.

Score Sheet for the Newest Vital Sign Questions and Answers

READ TO SUBJECT: This information is on the back of a container of a pint of ice cream.

	ANSWER CORRECT? yes	no
1. If you eat the entire container, how many calories will you eat? ***Answer:*** *1,000 is the only correct answer*		
2. If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have? ***Answer:*** *Any of the following is correct: 1 cup (or any amount up to 1 cup), Half the container Note: If patient answers "two servings," ask "How much ice cream would that be if you were to measure it into a bowl."*		
3. Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 g of saturated fat each day, which includes one serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day? ***Answer:*** *33 is the only correct answer*		
4. If you usually eat 2500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving? ***Answer:*** *10% is the only correct answer*		
READ TO SUBJECT: Pretend that you are allergic to the following substances: Penicillin, peanuts, latex gloves, and bee stings.		
5. Is it safe for you to eat this ice cream? ***Answer:*** *No*		
6. (Ask only if the patient responds "no" to question 5): Why not? ***Answer:*** *Because it has peanut oil.*		
Number of correct answers:		

Interpretation

Score of 0-1 suggests high likelihood (50% or more) of limited literacy
Score of 2-3 indicates the possibility of limited literacy.
Score of 4-6 almost always indicates adequate literacy.

APPENDIX H

Weiss et al. (2005) Screening Literacy Tool -Spanish

Información Nutricional

Tamaño de la Porción	½ taza
Porciones por envase	4

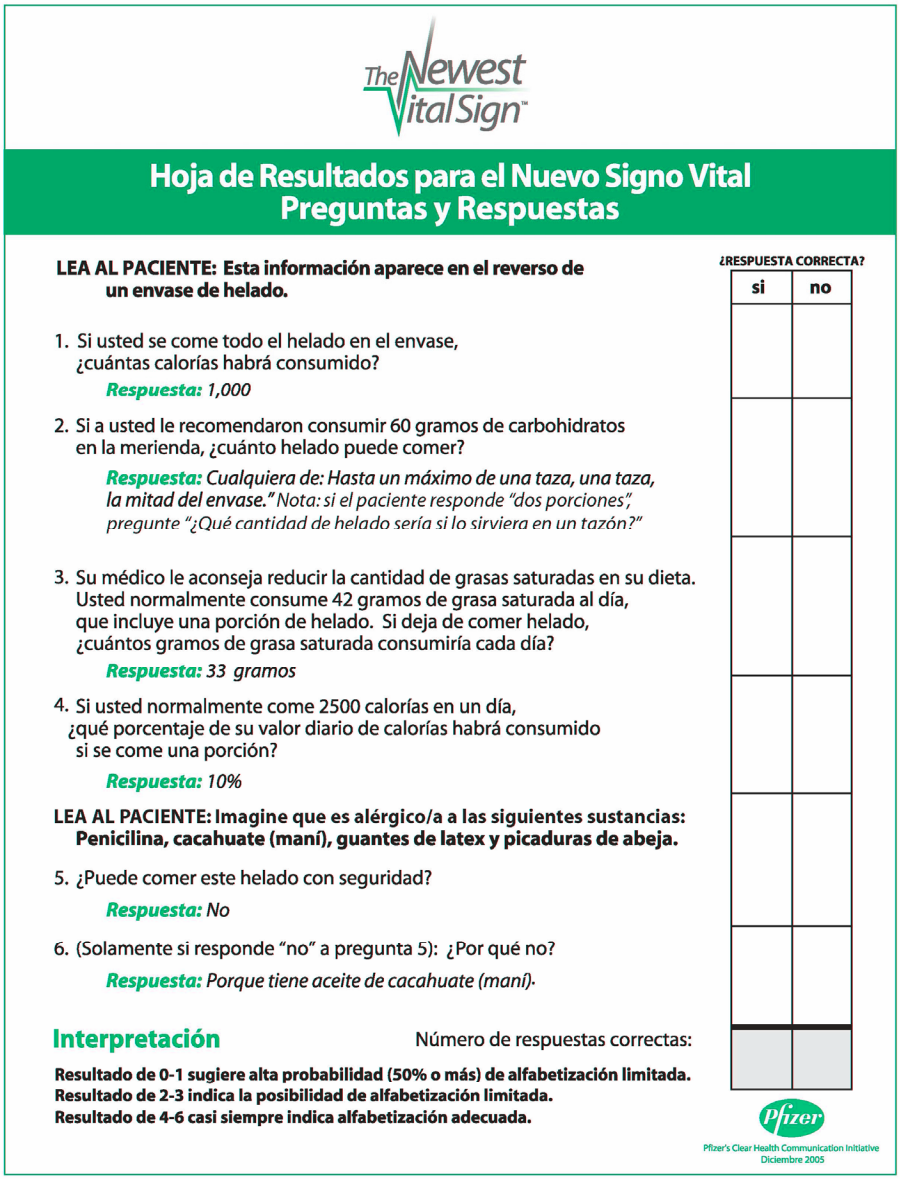
Cantidad por porción

Calorías	250	Cal Grasa	120

	%DV
Grasa Total 13g	20%
Grasas Sat 9g	40%
Colesterol 28mg	12%
Sodio 55mg	2%
Total Carbohidratos 30g	12%
Fibras Dietéticas 2g	
Azúcares 23g	
Proteína 4g	8%

*Porcentaje de Valores Diarios (DV) se basan en una dieta de 2.000 calorías. Sus valores diarios pueden ser mayores o menores dependiendo de las calorías que usted necesite.

Ingredientes: Crema, Leche Descremada, Azúcar Líquida, Agua, Yemas de Huevo, Azúcar Morena, Aceite de Cacahuate (Maní), Azúcar, Mantequilla, Sal, Carragenina, Extracto de Vainilla.



The Newest Vital Sign™

Hoja de Resultados para el Nuevo Signo Vital
Preguntas y Respuestas

LEA AL PACIENTE: Esta información aparece en el reverso de un envase de helado.

¿RESPUESTA CORRECTA?	
si	**no**

1. Si usted se come todo el helado en el envase, ¿cuántas calorías habrá consumido?
   Respuesta: *1,000*

2. Si a usted le recomendaron consumir 60 gramos de carbohidratos en la merienda, ¿cuánto helado puede comer?
   Respuesta: *Cualquiera de: Hasta un máximo de una taza, una taza, la mitad del envase."* Nota: si el paciente responde "dos porciones", pregunte "¿Qué cantidad de helado sería si lo sirviera en un tazón?"

3. Su médico le aconseja reducir la cantidad de grasas saturadas en su dieta. Usted normalmente consume 42 gramos de grasa saturada al día, que incluye una porción de helado. Si deja de comer helado, ¿cuántos gramos de grasa saturada consumiría cada día?
   Respuesta: *33 gramos*

4. Si usted normalmente come 2500 calorías en un día, ¿qué porcentaje de su valor diario de calorías habrá consumido si se come una porción?
   Respuesta: *10%*

LEA AL PACIENTE: Imagine que es alérgico/a a las siguientes sustancias: Penicilina, cacahuate (maní), guantes de latex y picaduras de abeja.

5. ¿Puede comer este helado con seguridad?
   Respuesta: *No*

6. (Solamente si responde "no" a pregunta 5): ¿Por qué no?
   Respuesta: *Porque tiene aceite de cacahuate (maní).*

Interpretación

Número de respuestas correctas:

Resultado de 0-1 sugiere alta probabilidad (50% o más) de alfabetización limitada.
Resultado de 2-3 indica la posibilidad de alfabetización limitada.
Resultado de 4-6 casi siempre indica alfabetización adecuada.

Pfizer

Pfizer's Clear Health Communication Initiative
Diciembre 2005

APPENDIX I

Pfizer Inc. Permission to Use the Newest Vital Sign

Pfizer Inc.
235 East 42nd Street, New York, NY 10017-5755

March 30, 2012

Ms Flores
[redacted]

Dear Ms. Flores,

Thank you for contacting Pfizer for permission to use the Newest Vital Sign. Pfizer is pleased to give permission for your requested use of the NVS, including the right to reproduce, display and distribute the NVS in connection with your dissertation. Please use the following attribution line: "NVS Copyright Pfizer Inc. Reproduced with permission."

Sincerely,

Jane Ungaro/RLP
Jane Ungaro

www.pfizer.com

APPENDIX J

Flyer

Are you a Mexican American woman?

Are you interested in participating in a research study?

We are interested in your opinion about Pap smears

Please call
For more details and qualifications

Bertha “Penny” Flores
PhD student
The University of Texas at Austin
210- 567-7101

APPENDIX K

Matrices Developed from Interviews

Fundamental Literacy Matrix

Score	Easy/like	Difficult/dislike	Willing to take

Science Literacy - Knowledge about Pap Smears Matrix

Important tests for women	Pap Helpful/ Impor-tant	Term Pap smear	Test for	Age to stop	What is difficult About Pap test	What type of provider	What pre-vents cervical cancer	Term. cervical cancer	HPV	HPV vaccine Recom. for younger women	What makes Pap easy/ difficult

Cultural Literacy and Pap Smears Matrix

Someone like you in mind	General attitude of friends/ family	Cultural views	Religious views	Mother's advice	Advice daughter /grand easy	Advice Daughters/ grand Difficult	Advice to women

Civic Literacy and Pap Smears Matrix

Obtain Health Info	Prefer to receive Health Info	What is helpful/like	Dislike

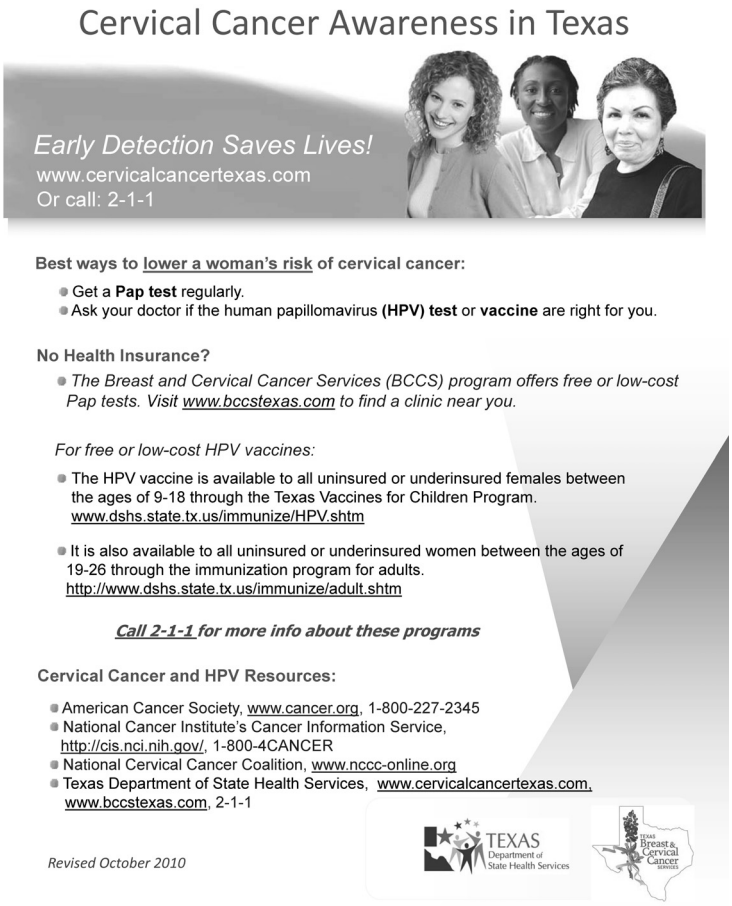
Media Literacy Matrix

Brochure/Texas Like	**Brochure/Texas Dislike**	**Texas/info**	**Brochure/CDC Like**	**Brochure/CDC Dislike**	**Internet use**

APPENDIX L

Texas Department of State Health Services

Cervical Cancer Awareness Brochure – English



Cervical Cancer Awareness in Texas

Early Detection Saves Lives!
www.cervicalcancertexas.com
Or call: 2-1-1

Best ways to lower a woman's risk of cervical cancer:

- Get a **Pap test** regularly.
- Ask your doctor if the human papillomavirus **(HPV) test** or **vaccine** are right for you.

No Health Insurance?

- *The Breast and Cervical Cancer Services (BCCS) program offers free or low-cost Pap tests. Visit www.bccstexas.com to find a clinic near you.*

For free or low-cost HPV vaccines:

- The HPV vaccine is available to all uninsured or underinsured females between the ages of 9-18 through the Texas Vaccines for Children Program. www.dshs.state.tx.us/immunize/HPV.shtm
- It is also available to all uninsured or underinsured women between the ages of 19-26 through the immunization program for adults. http://www.dshs.state.tx.us/immunize/adult.shtm

Call 2-1-1 for more info about these programs

Cervical Cancer and HPV Resources:

- American Cancer Society, www.cancer.org, 1-800-227-2345
- National Cancer Institute's Cancer Information Service, http://cis.nci.nih.gov/, 1-800-4CANCER
- National Cervical Cancer Coalition, www.nccc-online.org
- Texas Department of State Health Services, www.cervicalcancertexas.com, www.bccstexas.com, 2-1-1

Revised October 2010

TEXAS Department of State Health Services

Texas Breast & Cervical Cancer Services

Texas Department of State Health Services - Texas Breast & Cervical Cancer Services. (2010, Brochure) Cervical Cancer Awareness in Texas (rev. 2010). Retrieved from http://www.dshs.state.tx.us/bcccs/outreach.shtm

Texas Department of State Health Services

Cervical Cancer Awareness Brochure – Spanish

Concienciación sobre el cáncer cervical en Texas

¡La detección temprana salva vidas!
www.cervicalcancertexas.com
o llame al: 2-1-1

Las mejores maneras de hacer que baje el riesgo de que a la mujer le dé cáncer cervical son:

- hacerse la **prueba de Pap** regularmente.
- preguntar a su doctor si la **prueba** o la **vacuna** contra el virus del papiloma humano **(VPH)** son para usted.

¿No tiene seguro médico?

- *El programa de Servicios de Cáncer de Seno y Cervical (BCCS) ofrece pruebas de Pap gratis o a bajo costo. Visite www.bccstexas.com para localizar la clínica más cercana.*

Para vacunas contra el VPH gratis o a bajo costo:

- la vacuna contra el VPH está disponible para todas las mujeres no aseguradas o subaseguradas de 9-18 años de edad mediante el Programa de Vacunas para Niños de Texas. www.dshs.state.tx.us/immunize/HPV.shtm
- ésta también está disponible para todas las mujeres no aseguradas o subaseguradas de 19-26 años de edad mediante el programa de inmunización para adultos. http://www.dshs.state.tx.us/immunize/adult.shtm

Llame al 2-1-1 para obtener más información sobre estos programas

Recursos de cáncer cervical y VPH:

- Sociedad Americana del Cáncer, www.cancer.org, 1-800-227-2345
- Servicio de Información del Cáncer del Instituto Nacional del Cáncer, http://cis.nci.nih.gov/, 1-800-4CANCER
- Coalición Nacional del Cáncer Cervical, www.nccc-online.org
- Departamento Estatal de Servicios de Salud de Texas, www.cervicalcancertexas.com, www.bccstexas.com, 2-1-1

Modificado en octubre, 2010

TEXAS Department of State Health Services

Texas Breast & Cervical Cancer Services

Texas Department of State Health Services - Texas Breast & Cervical Cancer Services. (2010, Brochure) Cervical Cancer Awareness in Texas (rev. 2010). Retrieved from http://www.dshs.state.tx.us/bcccs/outreach.shtm

Appendix M

Centers for Disease Control and Prevention

Cervical Cancer Brochure - English

Cervical Cancer

Inside Knowledge
Get the Facts About Gynecologic Cancer

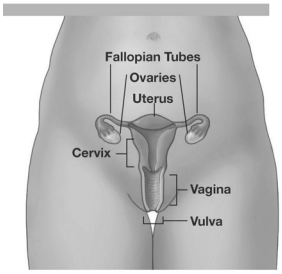
There are five main types of cancer that affect a woman's reproductive organs: cervical, ovarian, uterine, vaginal, and vulvar. As a group, they are referred to as gynecologic (GY-neh-kuh-LAH-jik) cancer. (A sixth type of gynecologic cancer is the very rare fallopian tube cancer.)

This fact sheet about cervical cancer is part of the Centers for Disease Control and Prevention's (CDC) *Inside Knowledge: Get the Facts About Gynecologic Cancer* campaign. The campaign helps women get the facts about gynecologic cancer, providing important "inside knowledge" about their bodies and health.

What is cervical cancer?

Cancer is a disease in which cells in the body grow out of control. Cancer is always named for the part of the body where it starts, even if it spreads to other body parts later.

When cancer starts in the cervix, it is called cervical cancer. The cervix is the lower, narrow end of the uterus. The cervix connects the vagina (the birth canal) to the upper part of the uterus. The uterus (or womb) is where a baby grows when a woman is pregnant.



Cervical cancer is the easiest gynecologic cancer to prevent with regular screening tests and follow-up. It also is highly curable when found and treated early.

Who gets cervical cancer?

All women are at risk for cervical cancer. It occurs most often in women over age 30. Each year, approximately 12,000 women in the United States get cervical cancer.

The human papillomavirus (HPV) is the main cause of cervical cancer. HPV is a common virus that is passed from one person to another during sex. At least half of sexually active people will have HPV at some point in their lives, but few women will get cervical cancer.

What are the symptoms?

Early on, cervical cancer may not cause signs and symptoms. Advanced cervical cancer may cause bleeding or discharge from the vagina that is not normal for you, such as bleeding after sex. If you have any of these signs, see your doctor. They may be caused by something other than cancer, but the only way to know is to see your doctor.

Are there tests that can prevent cervical cancer or find it early?

There are two tests that can either help prevent cervical cancer or find it early:

- **The Pap test (or Pap smear) looks for precancers, cell changes, on the cervix that can be treated, so that cervical cancer is prevented. The Pap test also can find cervical cancer early, when treatment is most effective. The Pap test is recommended for all women.**

  The Pap test only screens for cervical cancer. It does not screen for any other gynecologic cancer.
- **The HPV test looks for HPV—the virus that can cause precancerous cell changes and cervical cancer. Talk with your doctor, nurse, or other health care professional about whether the HPV test is right for you.**

Inside Knowledge is an initiative that supports the Gynecologic Cancer Education and Awareness Act of 2005, or Johanna's Law, which was unanimously passed by the U.S. House and Senate in December of 2006, and signed into law in January 2007.

www.cdc.gov/cancer/knowledge 1-800-CDC-INFO

Centers for Disease Control and Prevention Inside Knowledge. "Get the Facts about Gynecologic Cancer." Retrieved from http://www.cdc.gov/cancer/cervical/pdf/cervical_facts.pdf

When should I get tested for cervical cancer?

The Pap test is one of the most reliable and effective cancer screening tests available. You should start getting regular Pap tests at age 21, or within three years of the first time you have sex—whichever happens first.

The HPV test often is used to screen for cervical cancer, along with the Pap test, in women aged 30 years and older. It also is used to provide more information when a Pap test has unclear results.

If you are 30 or older, and your screening tests are normal, your chance of getting cervical cancer in the next few years is very low. For that reason, your doctor may tell you that you will not need another screening test for up to three years. But you should still go to the doctor regularly for a check-up that may include a pelvic exam.

It also is important for you to continue getting a Pap test regularly—even if you think you are too old to have a child, or are not having sex anymore. If you are older than 65 and have had normal Pap test results for several years, or if you have had your cervix removed (during an operation called a hysterectomy), your doctor may tell you it is okay to stop getting regular Pap tests.

What raises a woman's chance of getting cervical cancer?

Almost all cervical cancers are caused by HPV. You are more likely to get HPV if you started having sex at an early age, or if you or your partner have had sex with several others. However, any woman who has ever had sex is at risk for HPV.

There are many types of HPV. Usually HPV will go away on its own, but if it does not, it may cause cervical cancer over time.

In addition to having HPV, these things also can increase your risk of cervical cancer:

- Smoking.
- Having HIV (the virus that causes AIDS) or another condition that makes it hard for your body to fight off health problems.
- Using birth control pills for a long time (five or more years).
- Having given birth to three or more children.

How can I prevent cervical cancer?

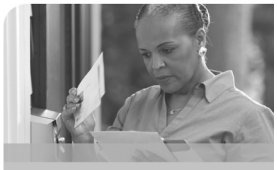
- Get the HPV vaccine. It protects against the types of HPV that most often cause cervical, vaginal, and vulvar cancers. It is given in a series of three shots. The vaccine is recommended for 11 and 12 year old girls. It is also recommended for girls and women aged 13 through 26 who did not get any or all of the shots when they were younger. (Note: The vaccine can be given to girls beginning at age 9.)
- See your doctor regularly for a Pap test that can find cervical precancers.
- Follow up with your doctor, if your Pap test results are not normal.
- Don't smoke.
- Use condoms during sex.*
- Limit your number of sexual partners.

What should I do if my doctor says I have cervical cancer?

If your doctor says that you have cervical cancer, ask to be referred to a gynecologic oncologist—a doctor who has been trained to treat cancers like this. This doctor will work with you to create a treatment plan.

Where can I find free or low-cost Pap tests?

If you have a low income or do not have insurance, you may be able to get a free or low-cost Pap test through the National Breast and Cervical Cancer Early Detection Program. To learn more, call 1-800-CDC-INFO or visit www.cdc.gov/cancer/nbccedp.



Where can I find more information about cervical and other gynecologic cancers?

Centers for Disease Control and Prevention: 1-800-CDC-INFO or www.cdc.gov/cancer

National Cancer Institute: 1-800-4-CANCER or www.cancer.gov

* HPV infection can occur in both male and female genital areas that are covered or protected by a latex condom, as well as in areas that are not covered. While the effect of condoms in preventing HPV infection is unknown, condom use has been associated with a lower rate of cervical cancer.

CDC Publication #99-9123, Revised May 2010

Inside Knowledge
Get the Facts About Gynecologic Cancer

Centers for Disease Control and Prevention

Cervical Cancer Brochure - Spanish

Cáncer de cuello uterino

Conozca Su Cuerpo
Infórmese sobre el cáncer ginecológico

Existen cinco tipos principales de cáncer que afectan los órganos reproductores de la mujer: de cuello uterino, ovario, útero, vagina y vulva. En su conjunto se les conoce como cánceres ginecológicos. (Un sexto tipo de cáncer ginecológico muy poco común es el cáncer de las trompas de Falopio).

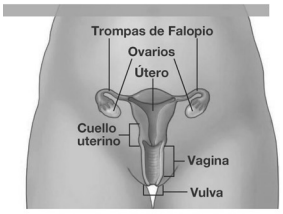
Esta hoja informativa sobre el cáncer de cuello uterino es parte de la campaña *Conozca su cuerpo,* una campaña nacional de concientización sobre los cánceres ginecológicos de los Centros para el Control y la Prevención de Enfermedades (CDC). La campaña ayuda a que las mujeres obtengan información importante sobre los cánceres ginecológicos, su cuerpo y su salud.

¿Qué es el cáncer de cuello uterino?

El cáncer es una enfermedad en la cual las células en el cuerpo se multiplican sin control. El tipo de cáncer se identifica de acuerdo a la parte del cuerpo en la que comienza, aunque después se extienda a otras partes del cuerpo.

Cuando el cáncer comienza en el cuello uterino, se llama cáncer de cuello uterino o cervicouterino. El cuello uterino es el extremo inferior y estrecho del útero. El útero es el lugar donde se desarrolla el bebé cuando una mujer está embarazada. El cuello uterino conecta la parte superior del útero con la vagina (vía del parto).

Con pruebas regulares y seguimiento, el cáncer de cuello uterino es el cáncer femenino más fácil de prevenir. Además, es muy curable cuando se detecta y trata en etapas tempranas.



¿Quién puede contraer cáncer de cuello uterino?

Todas las mujeres tienen riesgo de contraer cáncer de cuello uterino, pero esta enfermedad afecta con más frecuencia a mujeres mayores de 30 años. Se estima que cada año 12,000 mujeres en los Estados Unidos contraen cáncer de cuello uterino.

La causa principal de cáncer de cuello uterino es el virus del papiloma humano (VPH), un virus que se puede transmitir de una persona a otra durante las relaciones sexuales. Al menos la mitad de las personas sexualmente activas se infectarán por el VPH en algún momento de su vida, pero pocas mujeres contraerán cáncer de cuello uterino.

¿Cuáles son los síntomas?

En etapas tempranas, el cáncer de cuello uterino no suele presentar signos ni síntomas. En etapas avanzadas puede producir flujo o sangrado vaginal que no es normal para usted, por ejemplo, sangrado después de tener relaciones sexuales. Si presenta cualquiera de estos síntomas, hable con su médico. Estos síntomas podrían ser ocasionados por alguna otra causa, pero la única manera de saberlo es si habla con su médico.

¿Hay pruebas que puedan prevenir o detectar el cáncer de cuello uterino en etapas tempranas?

Hay dos pruebas:

- **La prueba de Papanicolaou puede detectar células precancerosas, cambios celulares en el cuello uterino que pueden ser tratados, así el cáncer de cuello uterino se puede prevenir. La prueba de Papanicolaou también ayuda a detectar el cáncer de cuello uterino temprano, cuando el tratamiento es más eficaz. Se recomienda que todas las mujeres se hagan la prueba de Papanicolaou.**

El único cáncer que puede ser detectado con el Papanicolaou es el cáncer de cuello uterino.

- **La prueba del VPH detecta el virus de VPH—que puede causar cambios celulares precancerosos y el cáncer de cuello uterino. Hable con su médico para saber si la prueba del VPH es adecuada para usted.**

Conozca su cuerpo es una iniciativa que respalda la Ley para la Educación y Concientización sobre los Cánceres Ginecológicos de 2005 (*Gynecologic Cancer Education and Awareness Act*). La ley también se conoce como la Ley de Johanna, la cual fue aprobada por el Congreso de los Estados Unidos en 2006 y promulgada a ley en enero del 2007.

www.cdc.gov/spanish/cancer/conozcasucuerpo
1-800-CDC-INFO (1-800-232-4636) Oprima 2 para español.

Centers for Disease Control and Prevention Inside Knowledge. "Get the Facts about Gynecologic Cancer." Retrieved from http://www.cdc.gov/cancer/cervical/pdf/cervical_facts_sp.pdf

¿Cuándo debo hacerme la prueba de detección del cáncer de cuello uterino?

La prueba de Papanicolaou es una de las pruebas más confiables y eficaces que hay. Usted debe comenzar a hacerse pruebas de Papanicolaou en forma periódica a los 21 años de edad, o en el período de tres años a partir de la primera vez que tuvo relaciones sexuales, según lo que ocurra primero.

La prueba del VPH se usa regularmente para detectar el cáncer de cuello uterino, junto con la prueba del Papanicolaou, en mujeres de 30 años de edad o más. También se usa para obtener más información cuando los resultados de la prueba del Papanicolaou son dudosos.

Si usted tiene 30 años de edad o más y los resultados de sus pruebas de detección son normales, su probabilidad de contraer el cáncer de cuello uterino en los próximos años es muy baja. Por esa razón es posible que su médico le diga que no necesita hacerse otra prueba de detección durante un período de hasta tres años. Aún así, deberá visitar al médico periódicamente para hacer su consulta de rutina que puede incluir un examen pélvico.

También es importante que usted siga haciéndose pruebas de Papanicolaou en forma periódica, incluso si piensa que es demasiado mayor para tener hijos o si ya no tiene relaciones sexuales.

Si tiene más de 65 años de edad y los resultados de la prueba de Papanicolaou han sido normales durante varios años, o si se le ha extirpado el cuello uterino (mediante una cirugía llamada histerectomía), su médico podría decirle que ya no necesita hacerse la prueba de Papanicolaou periódicamente.

¿Qué aumenta la probabilidad de contraer cáncer de cuello uterino?

Casi todos los cánceres de cuello uterino son causados por el VPH. Usted tiene más probabilidades de contraer VPH si ha comenzado a tener relaciones sexuales desde muy joven, o si usted o su pareja ha tenido relaciones sexuales con varias personas. Pero todas las mujeres que hayan tenido relaciones sexuales corren el riesgo de contraer el VPH.

Hay varios tipos de VPH. Por lo general, el VPH desaparece por sí solo, pero si esto no ocurre, con el tiempo podría causar cáncer de cuello uterino.

Además de VPH, los siguientes factores también pueden aumentar el riesgo de contraer cáncer de cuello uterino:

- Fumar.
- Tener una enfermedad que debilite su sistema inmunológico (como el VIH, el virus que produce el sida) que haga difícil que su cuerpo combata problemas de salud.
- Usar píldoras anticonceptivas por un largo tiempo (cinco años o más).
- Haber dado a luz a tres o más niños/as.

¿Cómo puedo prevenir el cáncer de cuello uterino?

- Póngase la vacuna contra el VPH. La vacuna protege contra los tipos de VPH que suelen causar con más frecuencia cáncer de cuello uterino, de vagina y de vulva. Se da en una serie de tres dosis. Esta vacuna se recomienda para niñas de 11 y 12 años de edad. También se recomienda para niñas y mujeres entre los 13 y 26 años de edad que no recibieron alguna o ninguna de las dosis cuando fueron jóvenes. NOTA: Esta vacuna se puede dar a niñas a partir de los 9 años de edad.
- Visite a su médico de forma periódica para hacerse la prueba del Papanicolaou que puede descubrir cambios celulares precancerosos.
- Hable con su médico si el resultado de su Papanicolaou no es normal.
- No fume.
- Use condones durante el sexo.*
- Limite el número de parejas sexuales.

¿Qué debo hacer si mi médico me dice que tengo cáncer de cuello uterino?

Pídale a su médico que la remita a un ginecólogo oncólogo, es decir, un médico especializado en el tratamiento de cánceres como este. Este médico creará junto a usted un plan de tratamiento.

¿Dónde puedo encontrar pruebas de Papanicolaou gratuitas o a bajo costo?

Si tiene bajos ingresos o no tiene seguro médico, puede hacerse una prueba de Papanicolaou gratuita o a bajo costo a través del Programa Nacional para la Detección Temprana del Cáncer de Mama y Cuello Uterino. Para más información, llame al 1-800-CDC-INFO (1-800-232-4636) y oprima 2 para español, o visite www.cdc.gov/cancer/nbccedp

¿Dónde puedo encontrar más información y otros cánceres ginecológicos?

Centros para el Control y la Prevención de Enfermedades:
1-800-CDC-INFO (1-800-232-4636)
Oprima 2 para español, o visite
www.cdc.gov/spanish/cancer

Instituto Nacional del Cáncer:
1-800-4-CANCER (1-800-4-226237)
Oprima 2 para español, o visite
www.cancer.gov/espanol

* La infección por el virus del papiloma humano (VPH) puede afectar los órganos genitales de hombres y mujeres, que se cubren o protegen con un condón de látex, así como las áreas que no se protegen. No se sabe con certeza si los condones previenen la infección por el VPH, pero su uso se ha asociado a una tasa más baja de cáncer de cuello uterino.

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Conozca Su Cuerpo
Infórmese sobre el cáncer ginecológico

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